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Testing Times

Exploring Everyday Life with Dementia
through Narrative-in-Action

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the degree of Doctor of Philosophy

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Declaration

I declare that this thesis is of my own composition, based on my own work, with acknowledgements of other sources, and has not been submitted for any other degree or professional qualification.

Karen A Barrie

Date: 16th August 2017

Lay Summary

This thesis explores the everyday lives of five older people with dementia and three spouses. All live at home in the same Scottish town, but have different life circumstances. There has been a tendency to think about the experience of older people with dementia as something singular and dominated by the condition, rather than recognising that each person has a unique life history, set of relationships, interests and concerns, and that his or her ongoing priorities in life may or may not relate to dementia. The study develops detailed understandings of the different ways that older people respond to, make sense of and live with a diagnosis of dementia.

The study uses a methodology called narrative-in-action, which draws on the philosopher Paul Ricoeur's thinking about the dynamic, circular relationship between narrative and life. The researcher met with each couple or individual seven times over a period of at least six months. During these meetings the researcher joined the participants in enacting activities of their choice within the home or the surrounding area, including the mundane activities that made up their daily lives plus other activities that they identified as important to them. The analysis of the data generated through these activities used Ricoeur's thinking.

The narratives highlight the obstacles, dilemmas and opportunities that the older people encounter and demonstrates how they negotiate them and contribute to ordinary social life. They illustrate the very different ways of responding to a diagnosis and the different part that dementia plays in the context of people's whole lives. The study considers these differences in light of the interplay between biography, relationships with contemporaries, predecessors and the next generation, and wider societal practices, including diagnostic practices and ongoing cognitive testing. The study offers an understanding of later life with dementia that is hopeful but not naïve. Possible future applications of the methodology and the narratives themselves are suggested.

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Dedication

This thesis is dedicated to my two late grandfathers, Lachlan 'Lachie' Mactaggart and William Douglas 'Dougie' Adam.

I wish that

I knew what I know now

When I was younger

Ooh la la....

Rod Stewart and the Faces

Abstract

This thesis explores the ongoing accomplishment of ordinary life with dementia and asks how older people variously negotiate and make sense of the obstacles, dilemmas and opportunities of everyday life as lived. The thesis responds to persistent calls to recognise the heterogeneity of people living with dementia and to challenge predominantly negative cultural stereotypes. It draws together parallel developments in contemporary dementia studies, namely the extension of social citizenship into the realm of the ordinary and fresh critiques of the biomedicalisation of ageing, particularly the rapid expansion of its technologies into the domain of cognitive impairment. In different ways, these developments bring a more overtly political impetus to the research agenda.

The research study takes the form of ‘narrative-in-action’ (Alsaker et al, 2009), a mode of Narrative Inquiry that combines Paul Ricoeur’s (1984) early narrative theorising with ethnographic methods. The study expands the theoretical underpinnings of this methodology by engaging more deeply with Ricoeur’s (1992) elaboration of the dynamic relationships between narrative and life, narrative and temporality, and incorporating critical insights from narrative gerontology. The resultant methodology facilitates an understanding of experiences as expressed in practice and through time by embodied, emotional, relational persons.

The study explores the everyday life of three couples, one man and one woman (aged 78-85 years) residing at home in a small Scottish town. This entailed meeting regularly with each person or couple over a period of six or seven months and participating in their choice of everyday activities. The length and intensity of involvement required careful deliberation about the creation and ongoing negotiation of uniquely constructed relationships that altered and deepened as the study progressed. Narrative analysis engaged with events, happenings and the various shifting and patterned meanings made within the flow of actions in different settings and over time, and was informed by Ricoeur’s (1984, 1992) notions of *mimesis*, emplotment and narrative identity.

The resultant narratives offer a nuanced understanding of different ways of living with dementia in later life. They illustrate how meanings were made in different situations and over time, depicting diverse implicit or purposeful ways of resisting the dominant cultural narrative of loss and contributing to ordinary social life. These distinctions were manifest in the dynamic, dialogic configuration of identities. Despite these

differences, the spectre of testing coloured each narrative, extending its reach into recollections of the past and also influencing the ways in which future possibilities were embraced, discounted or denied. This spectre also impacted upon the larger task of trying to make meaning of life as a whole in the face of ageing and memory loss.

The thesis augments current conceptualisations of citizenship-as-practice in dementia studies through the construct of recognition. It also highlights the potential of the narrative-in-action methodology to enrich the notion and study of 'narrative citizenship' (Baldwin, 2008); in this study, it facilitates an understanding of later life with dementia that is optimistic but not naïve. Taken together the narratives illuminate the risks of prescribing how people *should* respond to a diagnosis based on observations of how *some* individuals adapt successfully. Finally, the thesis concludes that unless we attend to productive as well as repressive forms of power, there may be increasingly testing times ahead for us all.

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Overview of the Thesis

This thesis presents the result of a doctoral research study. The study takes the form of Narrative Inquiry and asks how everyday life with dementia is accomplished by eight older people (three couples, one man and one woman) who reside in the same small Scottish town. This overview sets out what's in store, providing a short summary of each chapter. The thesis is presented in the traditional format, comprising introduction, literature review, theoretical and methodological frameworks, 'results' and discussion. As I do not introduce the people who took part in the study until Chapter Six, I open with *Dandelion Clocks*, a modern pantoum poem comprising one phrase expressed by each person - a poetic solution to my desire to foreground their unique contributions.

Chapter One, *The Political is Personal*, sets the scene. I provide a brief account of Narrative Inquiry and the requirement, as a narrative inquirer, to make visible and account for my presence in the research. I identify what I believed to be my motivation for undertaking the study as a specific concern about the UK policy push for earlier diagnosis of dementia sub-types¹, and the potential misrecognition of older people so diagnosed, later acknowledging that the study has deeply personal undertones. I reflect upon my personal experiences and connect with larger issues of social significance, raising questions that I then seek to address through a two-pronged review of the literature.

In Chapter Two, *Disentangling Ageing and Dementia*, I present the first part of the literature review, charting the history of the dementia phenomenon and its entanglement with the problematisation of ageing in Western society. The review brings together longstanding arguments concerning the biomedicalisation and politicisation of cognitive impairment in later life with fresh critiques prompted by the recent rapid expansion of biomedical technologies earlier into the 'disease process' and the catastrophisation of dementia discourse. I highlight what's at stake for older people and for society. In so doing, I renew the case for alternative social understandings of dementia, detect a growing interest in the 'ordinary doings' of people with dementia and identify a need for counter-narratives that bring humanity back into view.

¹ Dementia is a syndrome or collection of symptoms and cannot be diagnosed, only recognised. The different sub-types of dementia, such as Alzheimer's disease or vascular dementia, are diagnosable as diseases because they appear to have different manifestations in the brain, although as will be discussed, this distinction is less clear than usually presented.

In Chapter Three, *Dementia and Citizenship: Recognition Reconsidered*, I present the second part of the literature review, which considers the response of the wider academic research community to the dementia phenomenon. I trace the development of alternative social interpretations of dementia and the shifting focus of empirical attention. Detecting and responding to a persistent plea for ‘ordinariness’ from people living with dementia², I spotlight the potential of theoretical developments within dementia studies that emphasise narrative citizenship and extend consideration of citizenship-as-practice into the realm of ordinary life, augmented by wider arguments that foreground social recognition. I identify a gap in understandings of *how* everyday life (with dementia) is accomplished, together with the need for nuanced accounts that respect diversity and explore the complexities and dynamics of identity configurations.

Chapter Four, *The Bridge*, draws upon narrative theory to facilitate an exploration of the issues identified through the literature review, forging connections to the methodological approach taken in conducting the study. I first describe ‘narrative-in-action’ (Alsaker et al, 2009), a mode of Narrative Inquiry that combines Ricoeur’s (1984) narrative theorising on *Time and Narrative* with ethnographic methods. I explain how I established the potential to extend its application to a study of everyday life with dementia and engage with tensions between the increasing biomedicalisation of later life and pleas for ordinariness from older people living with dementia. I recount why, upon entering the field, I experienced a need to expand the study’s theoretical underpinnings by engaging more deeply with Ricoeur’s (1984, 1992) philosophy, and drawing insights from narrative gerontology. In *Oneself as Another*, Ricoeur’s (1992) extended account of the various meaning-making processes inherent in the nested levels of praxis that comprise our lives, I find support to consider the co-authored nature of our narratives, the dialogic nature of selfhood and forms of recognition. I conclude the chapter by setting out the methodological implications and research questions for the study.

In Chapter Five, *Carving a Path to the Domain of the Possible*, I document the methodological approach adopted to facilitate an exploration of everyday life as lived. In setting out the overarching research design, I discuss my commitment to participatory and ethical principles and the alignment of the chosen ethnographic data

² Throughout this thesis I use the term ‘people living with dementia’ to include both people diagnosed with a dementia sub-type and significant others who live with them.

creation methods. I reflect upon my experiences of finding a means of accessing participants with diverse backgrounds and current life circumstances and their recruitment to the study. This is followed by a brief summary of the time I spent in the field. A discussion of the narrative analysis process paves the way for consideration of criteria for determining the trustworthiness and authenticity of the results of the Narrative Inquiry.

In Chapter Six, *Opening Doors*, I introduce the people who participated in the study in the form of short pen portraits. Each portrait is followed by a thick description of the circumstances surrounding our introductory meetings, which surfaces questions about different understandings of 'everyday activities', the possibilities for doing everyday activities together and a summary of the ways we spent time together over the study period. I also consider the implications of the various understandings, possibilities for and enactments of everyday activities for the development of the research relationships and for gaining insights into each person or couple's everyday life.

In Chapter Seven, *Walkways*, I recount one particular experience of 'walking' out onto the three-dimensional Narrative Inquiry landscape and spending time with each person or couple. Each description is followed by an interpretation that draws upon narrative theory, connecting everyday activities with moral dilemmas, engaging with the how of meaning-making and forging connections between the past, present and implied future. I attend to the welcome and less welcome possibilities alluded to and conclude by considering the interpretive implications of the different 'walkways' taken.

In Chapter Eight, *Fallen Fruits*, I revisit, contextualise and expand upon the specific experiences detailed in the previous chapter, presenting the 'fruits' of the Narrative Inquiry in the form of five narratives plus supporting interpretations. In each case, I identify a plotline that connects various activities, events and happenings enacted or recounted over the study period. I ask what part 'dementia' does, or does not, play within the different narrative and narrative identity configurations. Each narrative conveys uncertainties regarding continued participation in and contribution to ordinary social life and the extent to which bodily ageing and local cultures open or foreclose opportunities for being and doing the things that the participants value, and are socially valued. The narratives depict diverse ways of resisting the dominant cultural narrative of loss. I also highlight the different ways in which spectre of testing colours each narrative, extending its reach across different temporal zones.

In Chapter Nine, *The Personal is Political*, I bring together the different elements of the thesis, reflecting upon the research questions through a social citizenship value lens by employing the EXPECT framework (Bartlett and O'Connor, 2010) as a heuristic device. Through its application, I consider the theoretical, methodological and empirical contributions of the research and reflect upon the participatory and ethical dimensions of conducting the study. I summarise the study's alignment with the need to adopt a more critical perspective in dementia studies and conclude by exploring options for translation of the study outputs into different fields of practice.

With *Endless Orchards*, the thesis concludes, as it began, with the words of the people who took part in the study.

Dandelion Clocks³

There's more to me than this; people forget
The love that I feel still grows
There's life in the old dog yet
Where there's life there's hope.

The love that I feel still grows
You can't turn back the clock
Where there's life there's hope
This life is all I know.

You can't turn back the clock
So much is lost in the mists of time
This life is all I know
Tis but a touch of frost.

So much is lost in the mists of time
There's life in the old dog yet
Tis but a touch of frost
There's more to me than this; people forget.

³ To tell the time by Dandelion Clock, you blow until the seed is all blown away, and you count each of the puffs, an hour to a puff. There is no singular 'right time'; unlike standardised, mechanical clocks, the time told by each person differs because we all blow differently. The poem title reflects my concern upon commencing this study that 'timely diagnosis' was being equated in policy with 'early diagnosis'. The pantoum poem 'recipe' was kindly supplied by Edel Roddy.

Chapter One

The Political is Personal

In the beginning, it was all black and white

Maureen O'Hara

Overview

This thesis makes an original contribution to knowledge by enhancing understandings of the narrative citizenship and social citizenship of older people living with the phenomenon we currently call “dementia”⁴. It charts a doctoral research study that develops a nuanced understanding of different ways of living with dementia in later life, adding to the ‘nascent field of academic narratives of resistance’ (Beard, 2016:232). Using narrative-in-action methodology (Alsaker et al, 2009), a form of Narrative Inquiry combining narrative theory and ethnographic methods, the study asks how everyday life is accomplished by eight older people (three couples, one man and one woman) living in a small Scottish town. This chapter sets the scene. It provides a brief account of the nature of Narrative Inquiry, traces the impetus for the research, establishes moorings for the study and identifies key questions to be addressed through a two-part review of the literature.

Narrative, Narrative Inquiry and the unmasking of the narrative inquirer

‘Narrative’ is used equivocally in qualitative research studies. I describe competing understandings of narrative, the Narrative Inquiry methodology and the theoretical underpinnings of narrative-in-action in detail in Chapter Four. In brief, ‘Narrative Inquiry’ is concerned with understanding people’s experiences and tries to make sense of life as lived (Clandinin and Connelly, 2000:78). It features to varying degrees the interplay between the researcher’s own subjectivity and the subjectivities of those whose lives and worlds are in view (Gubrium and Holstein, 2009). The narratives presented later in this thesis are derived from participant observation, when I join

⁴ This thesis questions the appropriateness and utility of the umbrella term “dementia” and welcomes its replacement in the 5th edition of the American *Diagnostic and Statistical Manual* (DSM-V) as a small step in a less stigmatising direction. Most study participants resist the term, preferring to talk about the specific form of ‘Alzheimer’s’ or ‘memory loss.’ Following the approach taken by Hughes (2013:12), I use the term as if it were unproblematic for pragmatic reasons and from here on without the “scare quotes” favoured by Gullette (2014:127) to aid readability.

Chrissie, Ann, John, Jim, Mary, Hector, Tommy and Grace in enacting and talking about the activities, events and happenings of their lives over several months. Through the resources of narrative-in-action (Alsaker et al, 2009) and narrative theory (Ricoeur, 1984; 1992) I attend closely to the various meaning-making processes of those whose activities, experiences and lives are under consideration. As a 'narrative inquirer' it is impossible (or self-deceptive) to stay silent (Clandinin and Connelly, 2000) or hide behind the mask of 'the researcher'. Throughout the study, I take special notice of my own participation, perspective, voice and emotional experience in relation to the experiences of those being studied and am mindful of my own narrative practices. This taking notice begins with my research interests, which emerge from my own narrative and shape the inquiry as whole. It is important to keep sight of topics of personal and social justification and I retrace the impetus for the research below.

The Black and White World of Beginnings

Before commencing this research study my world was rather black and white. I'd worked in Scottish health and social care service improvement contexts for many years, latterly with a focus on improving personal outcomes⁵ for older people. I became increasingly concerned about the influence of neo-liberalism and consumerism in mainstream UK health and social care policy, which together have privileged market mechanisms and individual choice-based models of support over relationality and collective responsibilities to meet needs for care (Barnes, 2011). Neo-liberalism is underpinned by the notion of the rational, autonomous, responsible, active citizen (Needham and Glasby, 2014). Bolstered by biomedicine, it equates difference with deficit and locates problems in individuals (Manthorpe and Iliffe, 2016) deflecting attention from societal ills. I observed the capacity of mainstream policy to marginalise older persons who do not live up to neo-liberal ideals (Barnes, 2011) and experienced difficulties in challenging it due to its unfortunate intertwining with seemingly progressive rights-based arguments that foreground individual choice and control (Needham and Glasby, 2014; Morris, 2011).

Following the introduction of dementia specific policy across the UK (Department of Health, 2008; Scottish Government, 2008), I was troubled by the political push for early, proactive diagnosis, particularly through the introduction of targets and

⁵ Personal outcomes are broadly defined as what matters to a unique and particular person in the context of his or her whole life rather than through the filter of diagnostic labels or services (Miller, 2011).

incentives. However, it was perceived limitations of post-diagnostic support provisions for people with dementia that motivated my decision to embark on a doctoral study. Or so I thought. In narrative thinking, ‘temporality’ is a central feature, requiring engagement with the complex interplay between past, present and future. In the course of completing the study, I’ve come to make connections with events and happenings from much earlier in my life, reinterpreting them in the perspectival light of the present, finding new meanings and appreciating their influence on my thinking. I have come to appreciate that what I thought was a socio-political interest in dementia has deeply personal undertones. As a narrative inquirer, inevitably I meet myself in the past and the implied future where there are no field texts, yet the experiences are very much part of the inquiry and have to be accounted for (Clandinin and Connelly, 2000). I reflect upon these experiences in the sections below.

Shades of Grey: Retracing the Four Moments in Conceptualising Dementia

My understanding of dementia has been shaped by prevailing societal understandings and various personal and professional encounters with people with dementia. How we as a society think about dementia matters because it speaks to the forms of human life that we value and the quality of human relationships (Downs, Clare and Mackenzie, 2006). How I think about dementia as a researcher matters as it determines the course of the inquiry. In documenting the impetus for the study and developing its overarching aim, a personal sense of justification is not enough. I therefore seek to use my shifting understandings of dementia over the last thirty-five years constructively, grasping together significant events and happenings, and locating them within what have been described as the ‘four moments’ in conceptualising dementia (Bartlett and O’Connor, 2010). Through this process, I identify and connect with larger issues of social significance. I raise questions pertaining to the history, biomedicalisation, politicisation and catastrophisation of dementia and the relationship with ageing, which guide a selective review of the relevant literature in Chapter Two. I also establish important markers for the conduct of the study, and I identify points of interest that direct my engagement with the academic literature to establish the theoretical orientation and empirical relevance of the research, as summarised in Chapter Three. In the sections that follow I retrace my shifting understandings of dementia from the first moment when dementia was regarded as ‘senility’, through biomedicine’s disease model, followed by Kitwood’s (1990) neuro-psycho-social conceptualisation to the

emergence of a 'fourth moment' that significantly recasts the social in considerations of dementia, bringing a social citizenship value lens to the fore (Bartlett and O'Connor, 2010).

The first moment: Dementia as senility -concealment and containment

My earliest encounter with dementia coincides with the 'first moment' of understanding, back when dementia was considered a fairly predictable if not inevitable sign of normal ageing, consigned to the realm of 'senility' and hence largely unremarkable and invisible (Cohen, 2006). My paternal grandfather, Lachie, was some sixteen years older than my gran, Nancy. A tall man with thinning grey hair, Lachie grew his own vegetables and wore cardigans with large leather buttons and I suppose I always thought of him as 'old'. When I was a child he handed out pan drops if my sister and I behaved, and cursed us in his native Gaelic if we did not. As a self-absorbed teenager in the early 1980s, I was vaguely aware that he was becoming 'a bit confused', but Nancy managed to keep the true extent of the changes in his cognitive condition hidden behind closed doors for quite some time. It was only when his physical condition also deteriorated that it all became too much for this diminutive and proud lady. Meeting the personal care needs of her much larger husband, helping him in and out of the bath or back on his feet when he fell on top of her was a physical impossibility.

I had left home to study when Lachie was admitted to a 'geriatric ward', confined within the walls of the old City hospital and I was told that he had 'gone senile'. I accepted this without question, not even a flicker of curiosity. I found the ward surreal, referred to it unkindly as the twilight zone, visited very infrequently and was relieved to be informed that there was 'no point' going back as 'he no longer recognised anyone'. Taylor (2008) suggests that the inability to recognise others may result in the person with dementia ceasing to be recognised, either as themselves or as a person. It is hard to pinpoint the emotion I felt when he died on Christmas Day in 1987; I had 'said goodbye to him' many years before.

I was largely protected from the details of Lachie's decline and from Nancy's struggles, but I do not look back on this period with rose-tinted spectacles. It now seems unthinkable that this way of ending a human life was countenanced just thirty years ago. My former self's attitude to 'old age' is also disconcerting, exposing the deeper issue of ageism and the relationship between age and dementia. In the next chapter, I

question the subsequent and ever-expanding biomedicalisation of cognitive impairment in later life and this sobering personal experience serves as an important marker, offering a valuable point of return.

The second moment: Dementia as disease -categorisation and cure

It was less than a decade after Lachie's death that my second closer and more prolonged encounter with dementia commenced. By the time Dougie, my maternal grandfather, began to show signs of forgetfulness, the 'second moment' had come to dominate. Specifically, 'dementia' had been adopted as an umbrella term for behavioural changes associated with various concomitant changes in the brain caused by a number of conditions. These include by far the most common form, Alzheimer's disease, but also vascular dementia and less familiar conditions such as dementia with Lewy bodies, Parkinson's dementia and frontotemporal dementia. Indeed, in the short interval separating the cognitive losses experienced by my two grandfathers, dementia and 'Alzheimer's' had become household names with highly emotive connotations, begging the questions how and why this paradigm shift came to pass. While some of the conditions finding shelter under the dementia umbrella are better understood than others, the net result was that deteriorating cognitive function in later life was relabelled a biomedical condition, characterised by a trajectory of irrevocable decline.

Dougie was 50 years old and a rather handsome and athletic man when I was born. His wife, Nan, died of a pulmonary embolism following a routine operation on my fifth birthday back in 1969. My sister was just a toddler at the time and my mum, still in her early twenties, was devastated. Our family life was turned upside down, Dougie spent a lot of time in our home and the two of us became 'good pals', we were 'as thick as thieves'. He remained a central figure in my life, assuming the role of great-grandfather to my children with enormous pride. In his early 80's, he became uncharacteristically uncertain. He was initially diagnosed with Alzheimer's disease, later revised to 'dementia with Lewy bodies', and his future laid bare – eventually he would 'forget how to swallow'. Until then his symptoms were to be managed through a trial and error medication regime, mostly error. As he lived alone, there was no one to conceal or contain the ravages of this condition. It was a fraught and distressing time for him and for my family.

Dougie suffered horrendous hallucinations and he became increasingly agitated and unpredictable. My parents tried hard to support him on a daily basis, but then came the

game changer; he started taking to the streets in the middle of the night, searching for his mother, who had died twenty years earlier, and a house that had since been demolished. Somehow, he'd find his way back hours later, freshly grief-stricken, and invariably having locked himself out. My parents were increasingly called upon in the small hours by an anxious neighbour, a frail lady a couple of years older than Dougie who lived directly below. I remember being called out on one occasion when my parents took a rare holiday, finding Dougie walking purposefully up a nearby street carrying a plastic bag containing clean socks, underpants, a toothbrush, an empty microwaveable fish pie carton and a red velvet bow tie. Back at his house we initially had a good laugh trying to imagine what the bow tie might have been for, but then I caught the look of fear in his eyes; it haunts me.

Dougie wanted to stay 'at home' and as a family we all tried hard to support this, but our efforts were doomed as he no longer recognised the place where he had lived for over fifty years as home, once familiar objects forgotten or obscured by the strange figures of his hallucinations. In contrast, his memories of his childhood home and the unconditional love that he had known there were crisp and clear, but the fragile tendrils rooting these images to the past were broken and he repeatedly tried in vain to return. Eventually this would-be time lord did not make it back from one of his nocturnal excursions. A kindly taxi driver found Dougie at three a.m. in the middle of a rain storm, lost, confused and soaking wet, and took him to the nearest hospital. He was admitted and my mum was told firmly that it was time to look for a care home. She found one, a far cry from Lachie's lamentable 'geriatric ward' and a pretty good choice all in all, given that no one in the family had any real idea what to look for. Dougie remained there for five years. I visited often and my son, just a young lad at the time, somehow, perhaps not seeing what I saw, managed to retain a special connection with his great-grandpa, filling me with bewildered awe.

This time I was very curious. Sadly, I asked all the wrong questions. My first degree is in Chemistry and I worked in informatics for the first phase of my career. Perhaps inevitably, I sought information on the neuropathology and symptoms, the mechanisms through which the various drugs were supposed to work, and of course the prognosis. Whenever I looked at Dougie I saw only the losses, the deficits and the ominous spectre of what was to come. In short, I subscribed to an exclusively biomedical understanding of dementia. Hughes (2011:128) has asserted that if one was 'to mistake the disease

model for the whole picture, the effect would be clinically, socially and ethically disastrous'. It was.

Over the years, concerns about Dougie's 'failing brain' were dwarfed by the failings of his body. He spent too many nights lying on trolleys in hospital corridors and survived too many 'scares', including a traumatic emergency operation to relieve a twisted bowel that remained undetected for far too long, defying all odds. I nicknamed him Lazarus, affectionately, and I suppose I expected him to 'keep going' forever. When he died on 27th October 2004 it was 'long overdue', 'a kindness', 'a blessing', but like every human life, his was irreplaceable and he left a huge hole and an unfathomable sadness. I miss him still. Looking back, my primary emotion is regret. His suffering at the end was undeniable, but there had been suffering much earlier too that I shied away from simply because I didn't know how to respond.

The literature on 'social death' (Sweeting and Gilhooly, 1997) whereby the person with dementia is no longer seen as being active in his relationships strikes a painful chord, although with a twist. Undoubtedly one of the more unusual books that I have read in the course of completing this study is Hallam, Hockey and Howarth's (1999) *Beyond the body: Death, dying and social identity*, which presents a new approach to the sociology of the body. It contrasts accounts of people who are biologically alive but socially dead with those of people who are biologically dead but socially alive. In amongst the weird chapters on ghosts, clairvoyants, zombies and vampires, I found more poignant accounts of the ways in which people continue to influence the lives of others long after their biological deaths. It is important for me to acknowledge Dougie's influence on my research. This influence has been much, much stronger than I appreciated at the outset, and at times has proved emotionally overwhelming.

Rather than trying to banish emotions to the side lines of the study, I have drawn upon them. Writing about the intelligence of the emotions, Nussbaum (2001) argues that emotions should not be dismissed as non-rational, but should be attended to in our deliberations because they have important things to say to us about what it is that we value. This experience reminds me of the practical issues and the roller coaster of emotions that we faced as a family when Dougie still lived at home. It has also pulled me back to earth whenever I was at risk of floating off and getting lost in the strange space of ontological and epistemological debate. I document it in some detail because it is a vital marker for the study, anchoring my commitment to contribute to an

understanding of dementia that is more optimistic, but without denying the existence of suffering and being honest about its different forms.

The third moment: Dementia reconsidered - care and compassion

It was just a few months after Dougie's death that my career took a rather unexpected turn, when the established tools of my trade in health informatics proved unable to accommodate the growing interest in 'patient experience'. Thanks to one imaginative geriatrician, I was plucked from my spreadsheets and thrust into the world of 'patient stories', quickly confronting our over-reliance on verbal communication. I had the opportunity to work with some remarkable practitioners who had a more hopeful understanding of dementia, characteristic of the 'third moment' and based on a humanistic, dignified and ethical approach. I was introduced, perhaps a little late in the day, to the work of Tom Kitwood (1990; 1997) who identified a lack of recognition of the person with dementia in institutional care settings. Challenging the attribution of the low level of interactions he witnessed solely to cognitive impairments, he expanded understandings of dementia. The old scientist in me was still seduced by formulae and I interpreted his position as an additive one, a synthesis, captured in the equation $D = NI + H + SP + B + P$ (where D is dementia, NI is neurological impairment, H is health, SP is social psychology, B is biography and P is personality).

In *Dementia Reconsidered*, Kitwood's (1997) insistence that the person comes first and that we must see the PERSON with dementia not the person with DEMENTIA jolted my thinking onto a different plane. The practitioners that I worked alongside sought to maintain 'personhood', (re)conceptualised as the 'standing or status bestowed on one human being, by another, in the context of relationship; it implies recognition, respect and trust' (Kitwood 1997:8). They encouraged me to enter into the PERSON with dementia's reality rather than imposing my own and I had the opportunity to support people through life story work and the creation of memory boxes. The experience was transformative and the importance of a relational understanding of 'personhood' stays with me. It is a third point of anchoring.

Emerging from this setting, I was initially upset and angry with myself, furious that I hadn't ventured into this goldmine before, but also perplexed as to why this understanding had remained confined to specialist dementia care settings. I was determined that at the very least 'no relative of mine' would be left in ignorance, but I soon discovered that my newly acquired insights were not always welcome. For

instance, when told that my great-aunt Ethel had started conjuring up a friend called 'wee Ethel', who only appeared in her bedroom, I quickly established that she had a full-length mirror on her wardrobe door. I suggested that perhaps Ethel was no longer recognising her own, now much smaller reflection, enthusiastically adding that her naturally warm disposition had served her well, as her instinct had been to make friends; had she been inclined to chase this 'visitor' away, the experience could have been altogether different. My enthusiasm was not reciprocated. I hadn't quite grasped Kitwood's point about not imposing our own reality on others. I also hadn't considered that the possibility of 'not recognising herself' might be far more unsettling than the rather sweet acquisition of an imaginary companion. The uniqueness of subjectivity is another important marker for the study and I develop my understanding of this in the chapters that follow.

Despite valuing this more relational perspective, I had a niggling feeling that the emphasis on memory boxes, life story and even personhood were concerned more with preservation than with future possibility. I wondered how useful this way of thinking would be around the time of diagnosis, at the time of the 'red velvet bow tie moment', or indeed at the end of life. In my day-to-day work, there was a growing worry that, unlike Kitwood's (1997) depiction of person-centred care, policy interpretations employed a highly individualistic notion of 'person', neglecting the importance of interpersonal relationships and the contributions that older people make. I was introduced to the thinking of Mike Nolan (Nolan et al, 2004; 2006) and found his account of relationship-centred care helpful in making these elements explicit, although its application was again largely confined to a few institutional care settings. Ultimately this experience raised questions about the continued domination of the disease model of dementia, which I explore in Chapter Two. It also surfaced some largely unformed concerns about possible limitations of understandings of dementia grounded in personhood and notions of person-centred or relationship-centred care. I revisit the strengths and limitations of this 'third moment' in Chapter Three.

The emergence of a fourth moment: Contextualisation, capabilities and citizenship

My understanding of dementia evolved again late in 2009 when I was introduced to members of the Scottish Dementia Working Group, bringing me to the emergence of a 'fourth moment' (Bartlett and O'Connor, 2010) in dementia studies. This 'fourth moment' is defined by the need to capture a more dynamic and critical perspective that

recognises the unique capabilities and contributions of persons with dementia as stakeholders in ordinary social life, values them as equal citizens and locates their experiences within a broader societal context.

I spent a considerable amount of time with one group member who gave me permission to use a collection of photographs that he had taken using a sophisticated camera, having been retaught the necessary skills by a support worker. *Was this even possible?* The collection was aptly called '*opening shutters, opening minds*', as I was amazed by what was being achieved through the campaigning efforts of the group members. These activists were challenging assumptions about what a person with dementia can do and highlighting some saddening experiences of discrimination. I was however struck by how relatively young the group members were, given that two-thirds of people with dementia in the UK are over 80 years old (Brayne and Davis, 2012). Although I accepted that it was perhaps inevitable that the campaigns were being led by the younger, fitter and more articulate minority, the experience nevertheless raised questions about both the thinking behind and consequences of this atypical portrayal of the human face of dementia, including the risk of rendering older or less capable people with dementia invisible. I also wondered if perhaps older people have different life priorities. This experience increased my interest in the relationship between ageing and dementia, which I explore in Chapter Two.

My questions resurfaced a short time later when I had the privilege of working with several older people with dementia (aged between 82 and 92 years) occupying the middle ground between the care home and the campaign trail. We created digital stories⁶ together to communicate their efforts to continue with the daily round of life at home and in their local communities with diverse levels of support. 'Dementia' occupied varying positions within these digital stories and, in some cases, it did not feature at all, with quite a few people preferring to regard their memory loss as part of the ageing process. Moreover, some people constructed positive personal accounts and others expressed unrelated concerns for themselves or family members. These short stories had a different 'feel' to them than those of the dementia activists and there was something 'extraordinary' about their ordinariness. Whilst sowing seeds of possibility for engaging with the more everyday practices of older people living with dementia,

⁶ Digital stories are short multi-media presentations combining spoken or written words, personal photographs, other still images and music, typically between three and five minutes long.

these did not germinate as I was diverted by the issues I encountered upon responding to a raft of dementia-specific policy imperatives, as discussed below.

The UK Policy Context, Politicising Diagnosis and the Risk of Misrecognition

My interest in dementia veered in a different direction following implementation of dementia-specific policy in Scotland, particularly the push for early, proactive diagnosis through the introduction of a national target (Scottish Government, 2008). Policy documents invariably present the benefits of early diagnosis as self-evident, although there are no efficacious treatments and diagnosis is not straightforward. I was troubled by the apparent lack of evidence to justify early diagnosis and struggled to see the difference between proactive case finding and screening, with dementia failing to meet the criteria for the latter. I also began to question the assumptions underpinning the estimated and projected prevalence of dementia and the alleged under-diagnosis of its various sub-types. And I was deeply concerned about the risk of failing to respect the unique perspectives and preferences of the persons and families concerned.

Some of my more basic concerns were partially alleviated by the subsequent policy guarantee of post-diagnostic support for one year (Scottish Government, 2013). I appreciated that post-diagnostic provision was based on sound evidence of what works for people who have purposefully accessed dementia-specific care and support services (Alzheimer Scotland 2012a, 2012b), but soon developed reservations about the capacity of the ostensibly 'person-centred', yet largely dementia-centric provisions to meet the varying needs of the diversity of people receiving a diagnosis. More fundamental questions about politically-driven diagnoses continued to niggle.

My concerns intensified when I participated in a post-diagnostic support implementation workshop in 2013, where practitioners reflected that although the model of support was 'just right' for some people, for others it was falling wide of the mark. This was attributed to it being 'too soon' for some people, while for others it was 'too late', calling to mind the story of *Goldilocks and the Three Bears*. Moreover, there was a disconcerting tendency to refer to people who resisted the diagnostic label, departed from the tale of tragedy (Basting, 2009) or did not fit within the parameters of 'expert' agendas and interventions as 'lacking insight' or 'in denial'.

I reflected back on my earlier digital storytelling work. 'Dementia' had occupied varying positions within the stories created and in some cases did not feature at all, but at the

time I'd viewed this absence positively and had not attributed it to lack of insight. My involvement however was brief and my role confined to facilitating the stories, rather than supporting or assuming responsibility for people's wellbeing going forward. The implications were quite different for encounters between specialist practitioners (whose 'success' was being tightly measured according to external criteria) and people recently diagnosed who 'lacked insight', were 'in denial', had different priorities, or simply did not want to allow 'dementia' to take centre stage in their lives at that point in time.

This brings me full circle to my original proposed starting point for the study. It touches upon the following argument:

'[S]ociologically, it would be hazardous and potentially unethical to extrapolate from observations of how some individuals or communities cope successfully with health challenges in ways which prescribe how others *ought* to behave' (Taylor and Bury, 2007:39 italics in original).

My practice observations also speak to more recent philosophical concerns about making normative assumptions about what should be important to people accessing health and social care services based on their diagnostic label and failing to recognise that they might be highly motivated to improve or maintain other aspects of their lives, thus restricting their opportunities (Entwistle and Watt, 2013). These assumptions may result in people's contributions and alternative narratives of wellbeing being overlooked, discounted or discredited. Such concerns run contrary to the idea that everyone's authenticity and quest for wellbeing is unique and should not be curtailed by the dominant order (Taylor, 2004). They allude to specific forms of misrecognition (Fisher, 2008; Honneth, 1996). I wondered what happened *within* these post-diagnostic practice encounters and with what consequence and I developed my original research proposal on this basis.

Looking Through the Other End of the Telescope

Upon commencing the PhD studentship in 2013, I gradually came to appreciate the limitations of my original research ideas. Specifically, although my professional interest in personal outcomes ensured that I was concerned with people with dementia in the context of their whole lives, I viewed practice encounters as my default entry point. My goal was to develop knowledge that would contribute to improvements in the lives of older people affected by dementia, but through the assumed medium of health and

social care practice and policy, a form a practice and policy myopia as result of working in these domains. Reflecting upon personal experiences concerning my two grandfathers reminded me of the relatively minor part that encounters with care services played in their stories, in their lives. A provisional review of the dementia literature also underscored the need for research that looks beyond the health and social care landscape, setting its sights on ordinary social life. I undertook to look at the research puzzle through the other end of the telescope, exploring everyday life as lived and attending to the neglected aspects of life, the opportunities entertained, the overlooked contributions and the alternative accounts of wellbeing.

The dominance of dementia as disease: Catastrophisation and colonisation

The study took further shape following an episode of Scotland Tonight⁷ on 11th December 2013 (the date then Prime Minister, David Cameron, pledged to double funding to find a cure for dementia). Five minutes of television served as an enactment of wider power plays. Grim forecasts of the scale and cost of the dementia ‘epidemic’ were presented, providing the backdrop to the search for a cure. The studio panel comprised a ‘person with dementia’ – a very smart and articulate man, a female carer, and a leading male representative from a dementia organisation. Slightly out of camera, a female academic tried to join the discussion by video-link. When the presenter asked the ‘person with dementia’ what it was like to suffer from dementia, he departed from the script, responding that he didn’t suffer, his memory loss didn’t concern him and that he had found new meanings in life through painting. I could scarcely watch as, in Hitchcockesque close-up, the presenter recoiled, unable to disguise her disbelief and discomfort. She turned swiftly to the carer who willingly supplied the expected tragic tale in response to the prompt, ‘but they call this disease the long goodbye’.

This painful viewing provided a very obvious reminder of the capacity of the media to foreclose the narratives of people with dementia through the deployment of metaphors of contagion and living death, and with far greater reach than direct care practices aligned to biomedicine. It caused me to question what other forms of misrecognition people with dementia negotiate in their everyday lives. I read with interest anthropologist Janelle Taylor’s (2008) account of staying in relationship with her mother through the advances of dementia. Taylor also finds people ready to embrace the narrative of loss, but disinclined to hear that she still enjoys her mother’s company.

⁷ <https://stv.tv/news/scotland/252656-scotland-tonight-how-can-we-better-care-for-dementia-sufferers/>

Thus, while my initial study ideas were concerned with diagnostic expansion, I found my own interests expanding to encompass the disease model's seepage into contemporary society, a form of colonisation (Manthorpe and Iliffe, 2016), and the catastrophisation of dementia in the media and wider public discourse.

Entering the domain of the possible

While acknowledging that many families may be less fortunate, Taylor (2008:324) argues that her experience with her mother's dementia is 'no "horror story"—and this, too, lies within the domain of the possible'. What struck me most about her account is that in seeking to challenge negative assumptions about life with dementia, she does not inadvertently reinforce Western society's 'action bias' (Hoggett, 2000; Madhok, 2013) that privileges individualist notions of responsibility, independence and active ageing. Adopting the broad research aim of *exploring everyday life with dementia*, I undertook to suspend assumptions and enter the domain of the possible too. In so doing, I adopted the overarching argument that the many alternative ways of understanding and responding to 'dementia' or memory loss in later life require equal consideration. Through my founding socio-political interests, I determined to locate the study within the 'fourth moment' of understanding and my reflections prompted me to attend closely to underpinning conceptualisations of what it is to be a person.

Reflections and Way Forward

This introductory chapter provided a brief introduction to Narrative Inquiry and the role of the narrative inquirer. I outlined the impetus for the research study, founded upon specific practice observations about the risk of care services making assumptions about what should be important to older people with dementia, foreclosing other possibilities and potentially resulting in secondary labelling. Through reflection upon formative personal encounters with people with dementia, I came to wonder what those other possibilities might be. I identified the importance of venturing out beyond the familiar health and social care landscape and developed the overarching study aim of exploring everyday life with dementia, locating my research interest within the 'fourth moment' of understanding in dementia studies. In so doing, I called attention to the deeper issue of ageism, competing notions of personhood, the uniqueness of subjectivity and the potential for misrecognition, which serve as important moorings for the study. The concerns and motives set out in this chapter are however based

primarily on limited personal observations, and the reflective process raised many, many questions:

How did the disease model of dementia come to the fore and why does it continue to dominate? What is the relationship between ageing and dementia? What's driving the political push for early diagnosis and the metaphorisation of dementia, and with what effect? How can the 'horror story' be reconciled with diagnostic expansion? Why are counter-narratives so readily discredited in the public domain, care practice settings and the private sphere? How far have we actually travelled since the redefinition of 'senility' in the 1980s? What are the limitations of understandings of dementia anchored by the notion of personhood? What promise does the emergent 'fourth moment' hold?

My world was no longer quite so black and white. To further develop my broad research aim, formulate the research questions, establish the theoretical orientation and empirical relevance of the study, I appreciated that I needed to embark upon a two-pronged review of the literature. In Chapter Two, I begin this process through a focused review that examines the entanglement of ageing and dementia, questioning how and why the disease model of dementia came to dominate, why its expansion continues, and with what consequences. In Chapter Three, I continue this process, turning to the literature documenting alternative social interpretations of dementia. I summarise what's known about the experiences of older people with dementia as stakeholders in ordinary social life, identifying aspects of the 'ordinary' that have been overlooked and theoretical lenses that may help to illuminate them. My approach to searching and reviewing the literature is detailed in Appendix I.

Chapter Two

Disentangling Ageing and Dementia

Overview

This chapter builds directly upon the motivations, interests, concerns and questions set out in Chapter One, where I established the overarching study aim of exploring everyday life with dementia. This chapter represents the first step in shaping the direction of the inquiry through a review of the literature. In the sections that follow, I look more closely at the entanglement of ageing and dementia and consider potential routes to the marginalisation of older people living with dementia. I detail the dividing practices associated with age-as-pathology and the dominant dementia-as-disease episteme, and consider the discursive work of metaphor. Consistent with the principles of Narrative Inquiry, I understand dementia practices and discourse as unfolding in time. I look to the past, to historical developments including the problematisation and (bio)-medicalisation of ageing before examining the specific case of the pathologisation and politicisation of cognitive impairment in later life. In so doing, I draw upon longstanding arguments from cultural anthropologists and critical gerontologists, moving into the present by introducing fresh critiques, sparked by the political push for early diagnosis of the dementia sub-types and the expansion of biomedical technologies earlier into the putative disease process. I look to the implied future, to the implications of new scientific discoveries and developments, revised demographic projections and the continued metaphorisation of dementia. I finally draw conclusions which serve as an analytical anchor for the study and inform the continued review of the literature in Chapter Three, where I consider alternative social interpretations of dementia and identify gaps in the knowledge base.

The Entanglement of Ageing and Dementia

Age is the single most important and universal risk factor for dementia (Lock, 2013). The sociological influences that frame the construction of dementia can be set against a more general reading of the attempt to bring the aged body under control (Elias, 1994) and under medical scrutiny (Davis, 2004). This attempt has rested on the scientific ability to identify dysfunction and pathology and ultimately to question whether old age per se is a normal physiological process or a pathological condition. Against this backdrop, the relationship between old age and (senile) dementia has constituted a

singularly thorny issue and the entanglement has been debated for more than a century. At the heart of the debate is the question of whether the most common form⁸ of dementia, Alzheimer's disease (AD), is a distinctly pathological state or a quantitative extreme of 'normal' ageing (Ballenger, 2006:6). Much hinges on this word 'normal', which I discover depends in large part on cultural and political influences on expectations about ageing (Lock, 2013). The terms of the debate have become more aggravated in an ageing world (Beard, 2016) and have recently been stoked again by dementia policies pushing for early diagnosis. In the sections that follow I look at the entanglement of ageing and dementia in more detail. I begin by reviewing the problematisation and increasing biomedicalisation of ageing and take forward the critical insights distilled when I consider the pathologisation, politicisation and catastrophisation of cognitive impairment in later life.

The Problematisation and (Bio-) Medicalisation of Old Age and Death

Ageing and death are universal phenomena. All cultures have methods of explaining and dealing with them and in the modern West the culture that performs that function is heavily framed by science (Vincent, 2006). Historical shifts in understandings of old age, the power and legitimacy that science gives to particular ways of understanding old age and the rise and dominance of medical definitions of the phenomenon have been extensively documented (e.g. Estes and Binney, 1989; Estes et al., 2003; Gilleard and Higgs, 2010; Lupton, 2000; Thane, 2000). Historical accounts point to critical transformations brought about by medical research in the nineteenth century. This research generated a set of ideas and associated practices that 'captured the aged body through three commanding perceptions' (Katz, 1996:40). These are (1) 'the aged body as a system of signification' – physicians examine bodies for indications that they mask 'inner states of disorder'; (2) the aged body as having a distinct pathology requiring medical therapy; and (3) the aged body as dying (ibid). As a result, 'the aged body became reduced to a state of degeneration where the meanings of old age and the body's deterioration seemed condemned to signify each other in perpetuity' (Foucault, 1973:41).

⁸ Figures vary and even those included in key policy documents are invariably generated by the Alzheimer's Association, but it is estimated that AD accounts for between 60% to as many as 80% of cases of dementia (Alzheimer's Association, 2015). This percentage is also likely to rise through the push for early diagnosis through memory clinics.

The entwining of science, welfare and healthcare

As the percentage of the population living into old age increased, a societal response was deemed necessary and the understanding of old age advanced by science became intertwined with welfare considerations. The social structures developed by modern society are intended to protect vulnerable individuals and society at large (Estes et al, 2003). There has however been a persistent tendency to meet the needs of the 'ideal' citizen at the cost of 'others' leading to their marginalisation and exclusion (O'Brien and Penna, 1998). In the process of securing a place for old age, ways of being old that were too uncivilised for society to tolerate demanded constraint or concealment, with many of the impotent poor confined to work house infirmaries (Elias, 1994).

Following World War II, a more optimistic attitude towards ageing emerged alongside a commitment to improving the lives of older people (Ballenger, 2006). Retirement became part of life and pensions were established. The downside of this intervention was the imposition of a structured dependency anchored by the reductive criterion of chronological age (Townsend, 1981). Attention also expanded from a preoccupation with the management of the aged poor to physical infirmity and the problem of old age became an issue within the health system (Gilleard and Higgs, 2010). Science indicated that infirmity was neither a natural nor an inevitable consequence of old age and the specialism of geriatric medicine developed, admirably aspiring to release older people from incarceration and 'rescue old age from the margins... to a real and valued position within society' [Warren, 1943 in Gilleard and Higgs, 2010:124]. This rescue operation was dependent upon the development of skills and practices to differentiate older persons with social needs from those whose needs stemmed from sickness and infirmity, and those who were remediable from the irremediable. It fell to science to supply the means. However, the anticipated reduction in the numbers of aged poor in effect resulted in a progressive rise in the numbers of older people occupying hospital and nursing home beds (Gilleard and Higgs, 2010).

Interweaving the threads of the market and the promise of successful ageing

In capitalist societies, the nature of welfare provision is influenced by market factors, the drive to make profit (Estes, 1979; Estes and Binney 1989; Robertson, 1990) and the industrio-medico complex (Estes, 2001). From the 1950s to the 1970s, old age was reconstructed as a time of independence from the demands of the labour force and support of children. The 'young old', mediated by market practices and electoral incitements, were set to age successfully, avoiding the stigma of physical and economic

frailty (Ballenger, 2006:7). Those imbued with a 'gerontological persuasion' argued that problems of ageing were pathological by-products of modern life, with older people 'made decrepit because modern society no longer made a place for them' (Ballenger, 2006:109). This argument persisted through the 1960s. By the 1970s, the market became more critical than welfare apparatus to available forms and narratives of successful ageing (Featherstone and Hepworth, 1991). A mix of market and welfare forms developed to meet the different needs of those who aged successfully and those who failed to do so (Manthorpe and Iliffe, 2016). With regard to the latter, the management of the rising numbers of older people requiring long-term care and the associated costs became the major source of policy preoccupation, rather than the redress of marginalisation or restoration of value (Gilleard and Higgs, 2010).

Promissory science and the biomedicalisation of ageing

Medicalisation – the expansion of medical jurisdiction, authority and practices into new realms – was first noted by Zola (1973). The 'problem' of the growing numbers of people reaching old age in recent decades has resulted in the massive expansion of the medicalisation of ageing and extensive industries to assess who is and is not part of 'normal' society (Katz, 1996). In 1989, Estes and Binney (1989) called attention to the influence of the 'biomedicalisation of ageing' on clinical practice, research and public opinion, suggesting that the construction of ageing as a process of decline, disease and decay brought it within the domain and control of biomedicine and was accompanied by the naturalisation and normalisation of medical intervention. The rapid pace of subsequent developments in the biomedical sciences and in geriatric medicine continue to shape knowledge about the aged body and expectations about intervention in later life (Kaufman, Shim and Russ, 2004), impacting on individual, family, medical and societal decision making. Despite some counter-narratives inviting mankind to come to terms with its mortality (e.g. Gawande, 2014; Hughes, 2013) this expansion continues amid allegations that the new longevity is creating the most expensive generation in history (Beard, 2016), casting ageing as a profoundly problematic burden on society.

Biological mutations and the cultural crisis of ageing

Determining where normal ageing stops and the pathological starts is a perennial problem, and the terms of the debate have mutated through more recent developments in biology and the study of the etiology and treatment of diseases at cellular or subcellular levels. The term 'biomedicine' masks a critical disciplinary rift between

medicine and biology (Vincent, 2006). At the boundary is the question of whether or not ageing itself should be considered a disease. As outlined above, as a result of developments in scientific knowledge, ageing progressively became associated with what went wrong, with failure. Within the bio-sciences, failure is associated with cellular maintenance and repair systems, such that ultimately old age can be constructed as a pathological condition which science has the prospect of curing (Vincent, 2006). Ageing is not called a disease because it is regarded as universal and natural, but this view has been challenged within the biosciences. At the core of this challenge is the rationale that if ageing is a disease, then it is possible to try to cure it. Without the label 'disease', research projects to discover successful interventions are unlikely to be funded (ibid). Cultural anthropologists underline how scientific activity is not always about uncovering "nature", but rather 'is a fierce fight to construct reality' (Graham, 2006:83). Rather than valuing life in all its forms, including the final stage, what has developed within this field is 'a process view that has detached old age from the level of the organism and the level of humanity' (Vincent, 2006:691).

Taking stock

In reviewing this literature, I am mindful of the apparent capacity of 'science' to alter meanings of 'old age', inform the practices that differentiate between 'normal' and 'pathological', legitimise and naturalise medical intervention, and denaturalise ageing and death. The concepts are not objective or given, but constituted in particular social and political contexts and elaborated over time as scientific knowledge changes and different pressures come to the fore. I recognise the need to keep sight of the ethical and political choices involved in what are reported as neutral positions of fact. The willingness within sections of the bio-scientific community to challenge what is taken as natural, universal and given and construct its own version of reality in the quest not for truth, but for research funding is noteworthy. Yet it also raises questions as to why these (re)constructions may be accepted more broadly, and what this says about our political and socio-cultural values. These strike me as very important handles to hold on to when considering the construction of dementia, particularly in its most common manifestation, Alzheimer's disease. I review the history of this construction below.

The Pathologisation and 'Alzheimerisation' of (Senile) Dementia

The thin line between normal and pathological is particularly contentious in the case of what was formerly called 'senility'. The extensive body of literature that documents and

critiques the pathologisation and biomedicalisation of ageing is complemented by volumes dedicated specifically to the history, medicalisation and politicisation of 'senility' and its putatively more palatable successor 'dementia'. The offerings are particularly rich with respect to the most common dementia sub-type, Alzheimer's disease (AD) (e.g. Ballenger, 2006; Basting, 2009; Beard, 2016; Bond, 1992; Cohen, 1995; Fox 1989, George and Whitehouse, 2014a; 2014b; George et al, 2012; Holstein, 1997; Leibing and Cohen 2006; Whitehouse and George, 2008).

The Alzheimer's story is long and murky, with a new chapter being written through the current push to extend the medical gaze earlier into the so-called 'disease process'. The political pressure has given rise to provocative and extensively researched accounts that not only review a rather dubious history and synthesise important arguments previously advanced by critical gerontologists, but also introduce fresh evidence of recent developments that challenge the dominant conceptualisation of Alzheimer's disease (Beard, 2016; Lock, 2013). In particular, anthropologist Professor Margaret Lock's (2013) *The Alzheimer Conundrum* draws upon in-depth interviews with eminent international psychiatrists, neurologists and neuro-geneticists together with potent insights from the British epidemiologist, Professor Carol Brayne. As late onset Alzheimer's disease is the most common diagnosis in the dementia stable and is shrouded in the greatest controversy, I look at these developments in closest detail. First, I consider the umbrella term 'dementia,' which in itself is not without terminological, conceptual or diagnostic difficulty.

Dementia: A useful classification heading or hollow label?

As noted in Chapter One, 'dementia' is an umbrella term, a heading in our established systems of disease classification encompassing a group of conditions that share the common characteristic of neurocognitive dysfunction. Until the end of the 19th century, dementia was a much broader clinical concept, encompassing mental illness and any type of psychosocial incapacity, including some that were reversible. In people aged over 65 years, senile dementia or senility was viewed as a normal if not inevitable aspect of growing old, rather than caused by any specific diseases (Berrios, 1990). Senility is now considered a derogatory term in popular discourse, but this was not always the case (Katz, 1996).

While the adoption of the clinical term 'dementia' encompassing a range of diseases worthy of medical care and attention may appear to represent an advance in medical

thinking and social awareness, it has not altered socio-political relations of domination and difference (Lock, 2013). Part of the problem is the term 'dementia' itself. Unlike the benign origins of senility, the word dementia derives from the Latin *demens* or *de mentis*— literally meaning out of the mind. In *Thinking through Dementia*, the philosopher Julian Hughes (2011) rejects dementia as a useful term, synthesising various medical and philosophical perspectives. Underscoring the importance of language, he suggests that terminology is a matter of morality and common humanity. On these grounds alone he contends that the term is insulting and stigmatising and should be abandoned. Clinicians too experience difficulty with the term because it is gloomy, distressing for people still capable of managing their lives and it contributes significantly to their reticence when establishing or disclosing diagnosis (ibid).

It appears that the medical community is beginning to take note and the term 'dementia' has been replaced with 'major neurocognitive disorder' in the latest version of the Diagnostic and Statistical Manual of Mental Disorders, DSM-V (American Psychiatric Association, 2013). Hughes (2013) questions whether we actually need a systematic classification heading to group the various sub-types. He adds that the alternative advanced by the DSM, although preferable, remains problematic as 'disorder' is morally loaded, suggesting something wrong as opposed to not working as well as it once did. Gullette (2014:127) who dislikes the term "dementia" intensely and only uses it 'in scare quotes', also welcomes the change in the DSM manual, observing that critiques culminating in the revision render "dementia" a hollow label, of limited diagnostic utility, combining categorical misclassification with etiologic imprecision. Nevertheless, she observes that the label — 'and its horrible vernacular forms, "dementing" and "demented" remain active, with malevolent effects' (ibid). While 'dementia' is entrenched in policy, services, academic literature and everyday language, thus making its replacement appear daunting, Hughes (2011) points out that other insulting terms such as mongoloid and moron have been eradicated not through scientific re-classification, but as result of consciousness raising. I endorse his conclusion that there are times when political correctness is warranted.

Dementia: The question of value judgements and the medical-moral tug-of-war

In addition to the regrettable terminology, the label raises diagnostic and conceptual difficulties (putting to one side the problem that a definite diagnosis can only be made post-mortem). According to the DSM-V, diagnosis calls for evidence of significant cognitive decline from a previous level of performance in one or more cognitive

domains of learning and memory, language, executive function, complex attention, perceptual-motor and social cognition. The cognitive deficits must also interfere with independence in everyday activities, such that, at a minimum, assistance should be required with complex instrumental activities of daily living. Separate diagnostic criteria exist for each dementia sub-type, although differentiating between these conditions is problematic and 'mixed dementias' are not uncommon. Conceptually, the DSM-V definition is limited in that the predominant focus on cognitive impairment and the 'loss of points on an intelligence test' (Hughes, 2011:17) detracts from a broader reality that includes the whole person. Further, Hughes et al (2006:2) highlight that the disease status is something to do with a failure of action or 'ordinary doing', which alerts us to the possibility that at the heart of the diagnosis 'lurks some sort of evaluative judgement'. The observation that there is no hard, scientific boundary between pathology and normality is not new, but the resultant need to reference functional abilities and thus introduce questions of value gives rise to a tug-of-war between medical and moral models (Hughes et al, 2006:3). The following quote cuts to the heart of the difficulties:

'Push the balance too far towards an exclusively medical model and this risks a slide from a properly medical role into coercive functions... but push too far towards an exclusively moral model and we end up denying the resources of medicine to those who most desperately need them' (Dickenson and Fulford, 2000:55 in Hughes et al, 2006:3).

Hughes et al (2006) comment that similar dangers lurk in our judgements about what will and will not count as normal ageing and normal forgetfulness. It is in respect of the latter that the most heated debates have arisen. People forget, particularly as they age and the threshold of 'ordinary forgetting' is highly ambiguous (Lock, 2013). In the next section I highlight that in the moral-medical tug-of-war over Alzheimer's disease, there are some heavy weights with political and industrial interests pulling on the medical end of the rope. The slide is well underway. A key question is which side are the onlookers cheering on?

The making of Alzheimer's disease: The dawning of a calculated politics of anguish

As indicated above, the history of Alzheimer's disease has been extensively documented but I consider it worth revisiting, both because many of the early ambiguities continue to haunt contemporary debates, and on account of the questions it raises about the location and enactment of power against a backdrop of supposed scientific certainty.

When in 1906 Alois Alzheimer described the clinical condition that now bears his name, dementia associated with old age was still considered an expected part of age-related decline. Alzheimer documented the first case of the condition when a woman, known as 'Auguste D,' presented in an asylum where he was working with behavioural symptoms remarkably similar to those observed in cases of senile dementia. She was fifty-one years old (Fox, 1989). Her condition deteriorated and she died four years later. Upon autopsy, her brain was found to contain the amyloid plaques and neurofibrillary tangles now associated with AD. In 1910 the eponym Alzheimer's disease was first used by the German physician Emil Krapelin when he registered it as a new disease category in the forerunner to the DSM. Dr. Krapelin asserted that what he observed in pre-senile patients (those under 65 years) was a new disease, distinct from senile dementia. The registration was based on only four cases, the neuropathology was not identical in each case and it took place despite the noted scepticism of Dr Alzheimer himself (George et al, 2012). Historians suggest Krapelin rushed the decision to register a new disease to promote his own interests (Hoff, 1991). The term AD thus originally related to dementia in people with pre-senile onset of symptoms, while 'senile dementia' was used when symptoms commenced in people over the age of 65 years and was not considered a disease per se (Lock, 2013).

In 1933, a study by German neurologists highlighted that the plaques and tangles of the type found in the brain of 'Auguste D' were present upon autopsy in 84% of persons dying over the age of 65, suggesting that the plaques are a normal part of ageing and causing the dementias to fall into a 'no-man's land' (Lock, 2013:37). By the mid-twentieth century, against the backdrop of a more favourable gerontological persuasion, as described previously, pathological interpretations of senile dementia gained currency (Beard, 2016). Competing theories were advanced centred on the relationship between mind and body. In contrast to the 'localisation theory' (Lock, 2013) which locates the problem firmly in the brain, some gerontologists considered ways in which mind, persons, life events, ageing and environments might interact to bring about neurological and behavioural changes that could become pathological.

However, the 'entanglement theory' (Lock, 2013:5) was dwarfed by the 'localisation theory' throughout the 20th century. In 1968, an extensive study showed that tangles like those found in 'Auguste D's' brain appeared in the brains of 62% of all older people upon autopsy (Blessed, Tomlinson and Roth, 1968). This was interpreted as indicative that AD was considerably more prevalent than first thought, and it seems the

possibility that the ageing process had been incorrectly medicalised was not countenanced (Beard, 2016). Throughout the 1970s, many leading researchers and neurologists contended that it was pointless to maintain a distinction between senile dementia and AD based on age alone, but struggled to gain support (ibid).

Fox (1989) points out that it was the serendipitous coming together of several forces rather than the generation of new scientific knowledge that caused this rumbling issue to finally capture the attention of the media and bring about the unification of pre-senile AD and senile dementia. In concert with the National Institutes of Health (NIH) in the USA, researchers and families of people affected by senile dementia united in search of diagnoses, treatment, support for family caregivers, and ideally, a cure (ibid). The Alzheimer Disease and Related Disorders Association (ARDA) was formed in 1980 to progress these concerns. Around the same time, it was reported that actress Rita Hayworth had the condition (Beard, 2016) and the resultant stimulation of public sympathy and support proved a critical ingredient. The power of science thus drew upon wider cultural and political influences on expectations about ageing and death. The unification transformed AD into the fourth or fifth leading cause of death in the USA overnight (Butler, 2008) and it has subsequently become a global policy concern. The unification also closed the door to alternative psycho-social, socioeconomic, political and public health arguments (Lock, 2013). In a personal communication to Fox, Robert Butler, the first director of the NIA, articulates his intention to claim Alzheimer's disease as a major research area for the NIA:

"I decided that we had to make it [Alzheimer's disease] a household word. I call it the health politics of anguish" (Fox, 1989:82).

It would appear he has succeeded. Fox (1989) indicates that the search for a cure is commendable, but the endeavour is a business with powerful economic interests. The seemingly questionable tactics deployed appear to be readily accepted within the neuroscience community. In conversation with Lock in 2008, neuro-geneticist John Hardy stated that the consolidation of AD as a singular condition was "**just** a political manoeuvre to get funding, and then **some people** actually came to believe that this is the case" (Lock 2013: 41, emphases added).

Politics, power and the sacrilegious

In calling attention to the political manoeuvring of the NIA, it is important to stress that the behavioural changes related to concomitant changes in the brain are undeniably

real and dementia has many causes, some of which are well understood (Lock, 2013). Moreover, there is broad consensus that early onset AD conforms closely to the plaque and tangle pathology first identified by Alois Alzheimer in 1906. For the majority of people diagnosed however, namely people over 75 years old who receive a diagnosis of the AD subtype, it is argued that there is something different at work (ibid). Key questions are why the unified biomedical explanation has been so readily embraced and with what consequence.

The vast majority of the subsequent billions of dollars of funding has been directed towards imaging techniques, memory clinics, diagnostic tools including reductive cognitive scoring mechanisms, pharmaceutical interventions of limited efficacy and the ongoing search for an elusive silver bullet rather than support for caregivers (Lock, 2013). This channelling of funds may have been expected to provoke a backlash from family caregivers who took part in the campaign. Fox (1989) points out that while the user movement in part sought support for caregiving, it also wanted senility recognised as a disease of the brain, challenging stigma and shifting moral responsibility for its occurrence. He concludes that the families had little time for competing psycho-social models of senility (ibid).

Drawing upon a Foucauldian analysis, Davis (2004) extends the rationale for acceptance of the dementia-as-disease episteme to the public, suggesting that sociological conditions enabled its propagation. He concludes that this construction must satisfy some productive element of power' (p371) namely producing a more palatably reassuring image of ageing. He proposes that it is better to witness armies of doctors and scientists making visible (with a view to possibly eliminating) the foundation of a disease than to fear a normalised deterioration without recourse to any structured cultural explanation. Hoggett (2000:44) also observes that to call attention and give some value to the immutable, untreatable and incurable has become deeply unfashionable, even sacrilegious. This would suggest that in this particular tug-of-war the onlookers tend to be on the side of medicine. As we move forward in time, a key question is whether the support will hold through unprecedented diagnostic expansion (Conrad, 2008) and the catastrophisation of dementia (Manthorpe and Iliffe, 2016), as discussed below.

A New Chapter: Looking at Recent Developments in the Artificial Light of the Lab

The contested relationship between ageing and dementia looks no closer to being resolved today, with many arguments becoming more acrimonious in an ageing world. Of particular note, as a result of recent findings in neurogenetics, epigenetics, epidemiology and genomics, a partial rethinking is taking place toward greater recognition of mind, body and environment entanglement, whereby neuropathology can be influenced by social circumstances, and vice versa. What appear to be opposites are interwoven in neuroplasticity, the malleability of a nervous system in contact with the outer environment (Lock, 2013:235). This expands Kitwood's (1990) account of the interplay between neuropathology and psycho-social factors, reaching far beyond the confines of the immediate care environment into local cultures and society and taking cognisance of entanglements over the entire life course. The symptoms and behaviour patterns we call dementia appear to be the outcome of accumulating exposures to harms or denial of protective benefits over decades (Drew, 2014). In the long term, this understanding paves the way for preventive approaches, more tractable by social, public health and wider societal means than by medical treatments (Lock, 2013; Wu et al, 2015). More immediately, it perhaps unexpectedly lends scientific credence to social interpretations of dementia characteristic of the third and fourth moments in understanding.

In parallel, advances in neuroimaging have confirmed what was once only available on autopsy, namely that one third of 'normal' living persons exhibit neuropathology in their brains (Lock, 2013:5). Recent predictions suggest that roughly 65% of people over the age of 80 would be diagnosed with AD or pre-disease based on imaging (Beard, 2016:29) and the plaques and tangles are sometimes not present in the brains of people diagnosed with AD (Kauffman, 2006; Lock, 2013). The assumed "factness" of Alzheimer's as a disease is now being questioned by a growing minority of experts' (Lock 2013: 7), with potentially profound implications for future research, policy, practice and public expectations, characterised by the diversion of the medical gaze.

Alongside these developments, news stories of breakthroughs consistent with the dominant 'localisation theory' continue to circulate and in the UK, policy continues to champion the search for a cure (Prime Minister's Office, 2015). The focus on the rising prevalence of AD puts the emphasis firmly on age, yet many research studies involve younger people without any comorbidities, making the results difficult to apply and potentially engendering false hope (Lock, 2013). Interestingly, although the value of the

market for medication to treat AD stood at more than \$3.7bn in 2013, there are signs that the pharmaceutical industry is losing enthusiasm for researching new treatments and is experiencing funding fatigue after a history of failures (Manthorpe and Iliffe, 2016). It is also increasingly emphasising improvements in behaviours and daily activities over memory in the promotional literature for existing products (Lock, 2013) and the potential for earning profits from dietary supplements for dementia prevention has also been noted (Thompson, 2014). Lock (2013) suggests the new emphasis on biomarkers seeking to identify biological changes in pre-symptomatic individuals is not only ethically questionable, but is also being hyped to deflect attention from the failure to achieve laboratory results and the low efficacy of available treatments.

The upshot of all this activity however is that the ontological question of what AD is and the epistemological question of the relationship of ageing and dementia remain unanswered; dementia and old age are deeply entangled (Lock, 2013). Despite this deep entanglement, the ageing of the population has fuelled even greater efforts to differentiate between normal and pathological ageing within the laboratory and in clinical practice. The pressing concern expressed by many observers pertains to the bioethical implications of the current push for earlier diagnosis of AD and related dementias. The uncertainties surrounding AD and dementia more broadly set out above cast the calls for proactive diagnosis in a dubious light and suggest that the value judgements that characterise the medical-moral tug-of-war may be inching over the midway mark of coercion. In Chapter Three, I review the literature concerning the everyday lives of older people with dementia, but for now I move closer to this sphere by stepping out from the artificial light of the laboratory into the shadowy middle ground of clinical practice.

Another Chapter: Entering the Shadowy Middle Ground of Clinical Practice

Much of the critique of the diagnostic expansion (Conrad, 2008) associated with dementia has been directed at developments in the USA, particularly the exponential growth of memory clinics. Some cognitive neuroscientists have also questioned their own validity claims (Moreno, 2009 cited in Gullette, 2014; Noë, 2009). A further source of controversy is the introduction of Mild Cognitive Impairment (MCI) as a disease category in the DSM-V, together with its ambiguous interpretation as a precursor stage for AD (Katz, 2017). However, the repercussions have been felt across the Western

world. In the UK, a core concern is whether the political push for early, proactive diagnosis crosses the mid-point of the moral-medical tug-of-war.

Politicising dementia and incentivising diagnosis

In England, dementia was first identified as a national priority in 2008 with the publication of the National Dementia Strategy (Department of Health, 2008; 2009). The previous year, the Scottish Government (2008) made dementia a national priority and set a target for improving diagnosis rates in 2008. This commitment to dementia has been refreshed and incentivised in different ways in subsequent dementia strategies and specific policy initiatives across the UK, with varying success. Of particular note, the Government in England introduced a financial incentive in 2013 to reward General Practitioners (GPs) for assessing patients aged over 75 years for dementia and cognitive impairment, but it was later withdrawn after GP representatives and patient groups fiercely condemned the payments as ethically questionable and damaging to the relationship between doctor and patient (Guardian, 2014).

In Scotland, the 2008 target to increase the number of people with diagnosis of a dementia was delivered and then replaced by a new national standard to maintain the proportion of people diagnosed on the Quality and Outcomes Framework (QOF) dementia register and other equivalent sources. The national standard is that two thirds of the estimated number of people with dementia should have a diagnosis with appropriate post-diagnostic support (NHS England, 2017). Although there is no direct financial incentive, the QOF represents one of the main sources of potential income for general practices across the UK (Information and Statistics Division Scotland, 2017).

Stretching the rules: Questioning the ethics of proactive case finding

The diagnostic push has sparked disquiet about the implications for older persons diagnosed with AD in its earliest stages (Beard, 2016), for older persons who have simply become forgetful (Brayne and Davis, 2012) and whose experience of later life may be marred by anxiety that they may become so (Spence, 2012). Population screening for dementia is not justifiable (or ethical) based on the current UK criteria, in that there is no effective treatment or evidence of better outcomes, no simple, safe screening tool, no detectable, understood disease course and no evidence of cost effectiveness (Manthorpe and Iliffe, 2016). Manthorpe and Iliffe (2016) suggest that the National Health Service has evaded its own screening rules by rebadging this as 'case finding', giving voice to a concern which triggered my decision to embark upon this study in 2013. In addition to the question marks surrounding the ethics of proactive

case finding, diagnostic targets and incentives, I was also motivated by concerns about the mechanisms used to measure progress against the target, which I consider below.

Lack of evidence: Putting the cart before the horse

The British epidemiologist⁹ Professor Carol Brayne (2007; Brayne et al, 2011; Brayne and Davis, 2012) has played an instrumental role in underlining the limitations of statistics used to communicate the actual and estimated prevalence of dementia in the population, nationally and internationally, including those used in conjunction with the UK national standard for diagnosis rates. Indeed, there are recent signs that the actual increase in the numbers of people developing dementia in some countries may have been over-estimated, probably unintentionally, with statistics indicating decreased incidence in several countries including the USA, England, Germany and Spain (Manthorpe and Iliffe, 2016). Brayne et al (2011) highlight that accurate assessment is simply not possible, suggesting that the fact that the number of cases and predictions about the impending catastrophe are reported with great assurance further muddies the water in terms of getting to grips with what AD is, how it relates to ageing and how best to confront it. Writing about the use of dementia statistics more broadly, Brayne and Davis (2012) stress that it is of crucial importance that approaches and findings are anchored to the reality of dementia in the true population if we are not to continue to drain public and commercial resources on the basis of overextended claims. Writing in the British Medical Journal, Brayne (2013) articulated concerns that the studies required to justify dementia screening have not taken place, calling this a case of putting the policy cart before the research horse.

Clinicians question the use of figures widely publicised by the Alzheimer's Society and UK Government to try to show the size of the problem, and consider their application to criticise GPs and the NHS more broadly for under-diagnosing in a bid to shame them into diagnosing more people a most unfortunate development (Brunet et al, 2012). The suggestion that clinicians are not acting in the best interests of people presenting with possible dementia has been refuted by narrative research unpacking the black box of timely diagnosis (Dhedi et al, 2014).

⁹ Professor Brayne is the Principal Investigator in a research program that commenced in 1985 that focuses on longitudinal population based studies of people aged 65 and over

Professional disagreements regarding pathological loss

Given the diagnostic ambiguity surrounding dementia and the inevitable recourse to value judgements, it is perhaps unsurprising that there is disagreement between the medical professions as to what constitutes pathological loss. Psychiatrists, geriatricians, general internists and GPs have been found to take very different approaches to diagnosis, focusing respectively on affective qualities, functional and global concerns in relation to neurological components, systemic signs and symptoms, and finally the ability of the person and the family to manage in everyday life (Graham, 2006). They may also reach different diagnostic conclusions (Lock, 2013).

Lack of evidence: Uncertain harms and benefits of diagnosis

The forceful promotion of the systematic identification of people with risk factors for dementia has been critiqued on the grounds that we do not know enough about the benefits and harms of doing so (LeCouteur et al, 2013). Whereas policy documents invariably present the benefits of early diagnosis as axiomatic, the medical press and academic research papers assert that the benefits of early diagnosis cannot be assumed (Dhedi et al, 2014). While some people may benefit in the short-term from pharmaceutical treatments, the gains at population level are minimal (Manthorpe and Iliffe, 2016). It is too early to reach a definitive conclusion about the merits of post-diagnostic support provisions and early evaluations of dementia adviser services indicate that there is no singular model on which to base service development (Clarke et al, 2013).

Concerns have been expressed about the possible harms associated with premature diagnosis and over-diagnosis (Brayne and Davis, 2012; Brunet et al, 2012; Dhedi et al, 2014; Spence, 2012). Diagnosis of a dementia sub-type is a complex medical and social practice, which involves balancing a range of judgements (Dhedi et al, 2014). Although most persons with dementia appear to adjust to diagnosis without seriously contemplating hastened death, some do consider it and express suicidal ideation and behaviour during the adjustment period (Draper et al, 2010). Moreover, a diagnosis can result in a 'defectological' view in which 'the afflicted person is defined principally in terms of catalogued dysfunctions' (Sabat 2001:10). This can restrict activities, compromise social relationships and result in well-meaning but overly protective measures by family members (Bamford et al, 2004).

For the above reasons, many GPs have argued against early diagnosis (LeCouteur et al, 2013), favouring timely diagnosis in line with bioethical recommendations (Nuffield,

2009). GPs are often also more inclined to understand how the person and family are coping with everyday activities and daily life rather than push for a precise diagnostic category (Graham, 2006). The diagnostic process itself has also been critiqued for its over-reliance on neuropsychological test batteries (Sabat, 2001) constituting symbolic violence (Smith, 2009) and taking the form of a degradation ceremony (Beard, 2016).

Dhedi, Swinglehurst and Russell (2014) highlight that expanding the diagnosis of dementia mostly increases profit for corporations and industries involved with developing screening and early-diagnosis tests, and pharmaceutical and complementary medicines marketed to maintain cognition in old age. Pharmaceutical companies sponsored the study that resulted in the above UK Government initiative that provided financial rewards for increased diagnosis rates, and funded the development of, and distribute, the Seven Minute Screen for dementia (ibid). There is therefore a serious risk that proactive diagnostic procedures and low efficacy medications will absorb resources that are badly needed for the ongoing care of people with dementia as it progresses (Lock, 2013). While my motivating concerns were primarily ethical and epistemological, I find the expenditure associated with this, at times unwelcome proactivity, hard to reconcile with the drastic cuts to social care services.

A final difficulty is that despite the putative diagnostic benefits of offering a legitimate explanation for changes in individual function and increasing community awareness of dementia, the social response has not improved in terms of removing stigma. Ballenger (2006) highlights the source of the stigma surrounding dementia is fear rather than ignorance, and clinical legitimacy is not the issue. The fear of dementia in the West has been attributed to our hyper-cognitive culture (Post, 2000), whereby the privileging of cognition and reason can result in cognitive impairment being equated with loss of self. Fear is also compounded by the catastrophic cultural representations of dementia, including the use of apocalyptic demography and the perpetuation of the individual horror story alluded to in Chapter One. I consider the implications of such representations below.

A Final Chapter: Looking at Dementia in the Harsh Glare of the Media

Cultural representations can serve to legitimise the status of persons who conform to the dominant norm whilst delegitimising and marginalising others (Plummer, 2003). 'Others' are marginalised and excluded in their day to day interactions with the world,

not only through social structures, but through representations and language used in both the public and private sphere. Institutionalised ageism coupled with negative cultural representations reinforce negative attitudes towards older people (Bond et al, 2004). The fear with which modern societies look on old age, impairment and death has been widely noted (e.g. Elias, 1994; Featherstone and Wernick, 1995). This fear is compounded by the threat of dementia (Beard, 2016).

More than a decade ago, Bond and colleagues (2004) suggested that in order to address the stigma surrounding dementia it will be at a societal level where most change must occur, reframing the issue as discrimination and drawing attention to the need for more positive cultural representations and narratives of older people with dementia. It would appear that positive portrayals do not serve the interests of those concerned with the generation of funding for scientific research. Having set out to create 'a politics of health anguish' through the unification of early and late onset dementia (Butler cited in Fox, 1989:8), Butler (2008) has more recently suggested that unless we find ways to prevent or cure Alzheimer's and other severe dementing diseases the world will shortly be confronted with... the epidemic of the 21st century. This depiction of dementia as an epidemic is only one of a number of emotive metaphors that is regularly deployed in dementia discourse, and the metaphorisation of dementia has recently become the subject of academic interest.

The metaphorisation of dementia

Researchers have critically examined representations of dementia in the media, both internationally (e.g. Clarke, 2006 (Canada); Kang et al, 2010 (USA) and Kirkman, 2006 (New Zealand)) and in the UK (e.g. Gordon, 2014; Johnstone, 2011; Mitchell et al, 2013; Peel, 2014; Zeilig, 2013). Zeilig (2013) makes an important contribution to considerations of the implications of the metaphorisation of dementia by looking at the way in which metaphor works. She highlights that by making an implicit comparison between two unlike things, whereby something unfamiliar is described by something that is familiar, both the principal and subsidiary subjects are transformed and yet preserved (Radley, 1993 in Zeilig, 2013). It is not only the similarity between the things compared that is important but also the difference. Through the combination of transformation and preservation, metaphors influence the way in which we perceive our worlds and therefore the way we explain and live in them (Zeilig, 2013).

Examining newspaper accounts, speeches by prominent politicians, documentary and feature films, Zeilig (2013) finds that patterned and systemic use of a range of metaphors about dementia pervades the popular imagination. Critical analysis reveals that discursive practices frequently equate the dementia phenomenon with disaster, a rising tide, a silent tsunami, an unstoppable force of nature. She detects an undercurrent of hysteria in many of the stories we are told about AD or related dementias (ibid). Most tellingly, metaphorical descriptions of dementia are readily found in medical and scientific texts and persistently conflate dementia with crisis. Zeilig (2013) also observes that the term dementia has itself become a metaphor for wider social ills. Peel's (2014) study of UK national newspaper articles identifies a 'panic-blame' theme, which again represents dementia in catastrophic terms (e.g. 'worse than death'), but notably also uncovers the promotion of a paradoxical representation focused on individualistic lifestyle changes and assuming individual responsibility to 'stave off', "fight" or "beat" the condition.

Johnstone (2011) exposes the problematic use of five key metaphors: the Alzheimer metaphor, reinforced by three additional metaphors, namely the epidemic, military and predatory thief metaphors; and the euthanasia metaphor. She stresses that while at one level 'the Alzheimer metaphor' might seem mundane, encompassing little more than the use of everyday language to describe and help give meaning to a perceived everyday reality of those diagnosed and living with the disease, this is an incomplete account of what the metaphor is achieving, particularly when reinforced by other metaphors. All metaphors were found to be morally loaded and used to stigmatise Alzheimer's disease (ibid).

Johnstone's (2011) analysis complements Zeilig's (2013) account of dementia as crisis, underscoring the ways in which metaphors de-humanise the person with dementia. For instance, the 'predatory thief' steals the inner being, such that what is left is a walking corpse, a zombie, a body left behind. Once de-humanised it is but a short step to regarding such persons as being of limited moral worth. This is a dangerous line of thought as the next logical step is that the cessation of life is made comprehensible. Indeed, Johnstone (2011) uncovers a particular issue through the use of metaphor as an end-of-life 'solution' for people with dementia within the debate on the legalisation of euthanasia / physician assisted suicide. With euthanasia depicted as beneficent, the 'Alzheimerisation' of the euthanasia debate (ibid) brings death back into the frame.

Dementia and dementia discourse throw up deeper, philosophical issues about the value we attach to different forms of human life (Hughes, 2013). As biomedical technique has extended choice to every aspect of existence, death is often a matter of choice and it seems there is a responsibility to choose (Kaufman, 2006). Strong ambivalence has come to haunt the value of the lives of persons with advanced dementia. In recent years, there has been a palpable shift in public attitudes and beliefs about the desirability and moral permissibility of euthanasia and physician-assisted suicide as an end-of-life 'solution' for people living with Alzheimer's disease, not just at the end stage of the disease, but also at its beginning stage (Hertogh, 2009). Perhaps the real tragedy of Alzheimer's is the tragedy of our attitude to life (Hertogh et al, 2007). The unwelcome "war" that we have been conscripted into appears to be a culture war, and 'no other ongoing culture war dares to call so openly for the death of its victims' (Gullette, 2014:134).

The above analyses of cultural representations of dementia underscore just what's at stake for older people and for society. They must be set alongside the questioning of the assumed 'factness' of Alzheimer's as a disease (Lock, 2013: 7). Beard (2016:229) states that we must ask ourselves what early diagnosis means, sociologically speaking, for all of us as we ourselves age and anticipate ourselves as future old people. She adds that bioethical discourse must attend to the potential effects of medical reductionism on the everyday lives of people who may be deeply forgetful (ibid). This body of literature suggests to me that the search for pathology is seriously misdirected, with the major pathology located not in aged brains, but in society itself. There has been a failure in the external ecology of relationality and recognition (Jennings, 2017).

Reflections and Way Forward

This chapter has considered the mutability of the normal: pathological divide, and the role of science in constructing old age as progressive decline and naturalising medical intervention in the domestic and social lives of older people (Robertson, 1990). The decision to include senile dementia within the Alzheimer's disease category took place against this backdrop, opening up the possibility of finding biomedical means of cure and treatment and authorising socio-cultural norms. The biomedical understanding of dementia is flawed yet has come to dominate, colonising everyday life (Manthorpe and Iliffe, 2016). Its expansion is fuelled by catastrophic cultural representations and increasing politicisation, driven by the need to be seen to do something, rather than

evidence-based decision making. The questionable push for earlier diagnosis at a time when the 'assumed factness' (Lock, 2013) of AD is increasingly being questioned may stretch the frayed medical-moral tug-of-war rope to breaking point. This has numerous implications, but we cannot turn back the clock to the time when senile dementia was considered part of ageing. My memories of visiting Lachie in the abominable geriatric ward intimate that we should not aspire to, and the productive power of the disease model proposed by Davis (2004) cannot be discounted.

Fresh insights, such as those distilled by Lock (2013) and Beard (2016), underscore the need to divert our gaze away from the lab and the memory clinic towards psycho-social approaches and longer term public health preventive efforts, which would require major changes in economies and in society. Peel's (2014) review of UK newspaper articles serves as an early warning of the need to remain alert to the risk of shifting responsibilities onto individuals, should a more preventative agenda take hold. These insights also underscore the need to draw upon social interpretations of dementia, which I review in Chapter Three.

Whether or not 'normal' ageing is a disease, or senility in old age is normal are questions that existed long before recent forms of medico-cultural negotiation emerged (Kaufman, 2006). What is at stake within the current debates is that, at the boundary between life and death, the common denominator is the detachment from humanity. This holds whether with recourse to intra-cellular activity in the bid to evade ageing or death by reconstructing old age as a pathology that may be cured, or forging associations with non-human forms to endorse euthanasia for a life already tainted by death. There is a desperate need to bring humanity back in. And there is an urgent need for less disastrous or horrific cultural representations of dementia. An inspiring culture of ageing needs critically interrogative narratives, inspiring counter-narratives (Baars, 2012) and a new moral vision (Jennings, 2017).

Manthorpe and Iliffe (2016) draw upon Bender's (2003:55-79) analysis of why the biomedical understanding of dementia is so dominant, despite its weaknesses. As discussed in this chapter, contributory factors identified include the issues of changing demography and estimated costs, the profit-seeking ethos of the pharmaceutical industry, the fear of dementia and the resultant desire for a cure, and the favouring of 'brain disease' explanatory models within the better resourced medical specialities (ibid). In addition, the list includes the interest of academia in framing problems in

particular ways so that they can then solve them. In progressing this study, I am therefore mindful that a biomedical label not only easily occludes the everyday lives of people so labelled, but can also shape research questions and influence the knowledge produced (Alsaker and Josephsson, 2011).

Manthorpe and Iliffe (2016:24) do not underestimate the difficulties of changing the ways in which people think about dementia and replacing the powerful metaphors and narratives that construct these thought processes, yet believe it is possible. I agree. I suggest that a useful place to start is by following Taylor (2008) into 'the domain of the possible' and attending closely to the possibilities entertained, pursued and actualised in the everyday lives of older people with dementia, without neglecting those possibilities discounted, discouraged or denied.

This chapter has drawn up the thoughts of philosophers, sociologists, anthropologists, epidemiologists and GPs, all of whom, in different ways, have articulated the need to move away from the preoccupation with diagnosis and look at the person and how s/he manages in daily life. Even the pharmaceutical industry and the media may be resetting their sights on everyday activities and lifestyles! Going forward, the focus on 'ordinary doing' (Hughes et al, 2006) seems set to intensify. In Chapter Three, I ask what's already known about the 'ordinary doing' and the everyday lives of older people affected by dementia and identify a gap in our understanding. I also seek theoretical support to enable me to pursue this line of inquiry by reviewing alternative social understandings of dementia and notable developments in citizenship studies more broadly. In so doing, I hold on tightly to both the pervasiveness and limitations of biomedical understandings as important analytical anchors.

Chapter Three

Dementia and Citizenship: Recognition Reconsidered

Overview

This chapter complements and builds upon the literature review presented in Chapter Two, which recounted and critiqued the history, dominance and continued expansion of the biomedical understanding of dementia. Revisiting this literature was of value, identifying fresh sources of support for ‘entanglement theories’ of dementia and discerning potential future interest in ‘ordinary’ doing. In this chapter, I identify a lack of attention to *how* an ordinary, everyday life is accomplished, despite persistent pleas for ordinariness from older people living with dementia. I review theoretical perspectives that advance alternative social interpretations of dementia, tracing early applications of the social model of disability to cognitive impairment and the subsequent reframing of arguments through an inclusive and relational understanding of citizenship-as-practice. I then summarise specific developments within this understanding, notably dementia activism, expansion of the social practices of citizenship into the realm of ‘the ordinary’ and calls for a narrative citizenship in dementia studies. More broadly, I consider the focus on recognition as a vital aspect of citizenship. In so doing, I consider the distinctive contribution of an ‘ethic of care’ perspective, notably in problematising the private: public divide and exposing ageist and gendered assumptions regarding contemporary Western understandings of ‘achievement’.

Shifting Understandings of Dementia Revisited: The Limits of the Third Moment

As set out in Chapter One, there has been a series of moments in understandings of dementia over the last 35 years in Western society, signalling marked shifts in values, power relations and the construction of subjectivity and agency (Gilmour and Brannelly, 2009). For many years the person with dementia was reduced to sufferer, inscribed as subaltern (Gilmour and Brannelly, 2009) and rendered invisible. The introduction of person-centred care (Kitwood 1990; Kitwood and Bredin, 1992; Kitwood, 1997) sought to reclaim personhood, restoring the visibility and voice of the PERSON with dementia. Kitwood’s work transformed dementia care practices, redressing the ultimate act of exclusion by encouraging us to think afresh what it means to be a person and underscoring our relationality and unique subjectivity.

However, Kitwood's (1997) methods have been criticised as pseudo-scientific and lacking validity (Davis, 2004; Dewing, 2007). Moreover, his conceptualisation of personhood has been identified as facing several limitations, as summarised below.

First, depicted as a 'status bestowed' by caregivers, personhood reclaims the person with dementia as someone who matters, but does not necessarily suggest agency (Bartlett and O'Connor, 2010). Secondly, although posited as a psycho-social extension to neuropathology, this understanding tends not to truly enter into the social realm, instead remaining at the level of the basic psychology of the individual (Baldwin and Capstick, 2007; Hulko, 2004). Thirdly, while stressing the importance of eliciting the experiences of people with dementia, the emphasis has been on perspectives as they relate to experiences of care, within the context of caring relationships, plus responses to diagnosis and coping mechanisms. Finally, the privileging of the relational self overlooks a vital part of selfhood inherent in our embodied existence, denying the body any intentionality or agency (Kontos, 2004). In view of these limitations, steps have been taken to bring the body back into view (e.g. Kontos, 2012; Watson, 2016) and to further the enactment of social justice in relation to people with dementia by advancing more overtly socio-political interpretations. Social citizenship has emerged as a key concept for dementia studies and practice (Bartlett and O'Connor, 2007).

The limitations of the established body of empirical research in dementia studies have been a key driver for the introduction of a social citizenship value lens. Nevertheless, innovative research methods and earlier diagnosis have made it possible to 'hear more voices' of older people living with dementia and the literature does provide important insights of direct relevance to this Narrative Inquiry. I provide a necessarily brief summary of the most salient insights from the more established literature below, then devote the remainder of the chapter to the 'fourth moment' in dementia studies, particularly the literature pertaining to dementia and citizenship.

Discerning a Plea for the Ordinary

In Chapter Two, I highlighted the concern that exclusively biomedical understandings not only risk occluding the everyday lives and meanings of people ascribed a diagnostic label, but can also frame research questions and influence the knowledge produced (Alasaker and Josephsson, 2011). This concern was substantiated by a selective review of the literature regarding the experience of dementia, using the approach described in Appendix I.

The overall picture is one where most older people do adapt to a diagnosis and systematic reviews have found a high degree of consistency in the range of coping strategies identified across studies (Steeman et al, 2006; 2007). Of particular interest to this study, the review highlights that many older people with dementia contextualise their experiences within normal old age, rather than understanding dementia as a disease (Gillies, 2000), need not perceive it as a problem (Phinney, 2002) and prefer to talk about having memory problems or being forgetful (Langdon et al, 2007).

There are persistent pleas for an 'ordinary life' from older people living with dementia (e.g. Beard, 2004; Hulko, 2009; Steeman et al, 2006; Von Kutzleben et al, 2012). Similarly, other studies highlight that older people strive for 'normalcy' and may redefine what is normal (e.g. Cheston and Bender, 2003; Gillies, 2000; Hulko, 2004; Lyman, 1998; Phinney, 1998). Older people do not have to accept the diagnosis to enjoy a good quality of life (Beard, 2016). Age can mediate the meaning of illness (Pearce et al, 2002) and dementia may pose a lesser threat when it occurs later in the life course.

Importantly, the review found that it is possible to reject the dominant cultural narrative of loss and incorporate dementia into a positive story of living (e.g. Beard et al, 2009; Cheston and Bender, 2003; Dorenlot, 2005; MacRae, 2008; Steeman et al, 2007). Some people use the disease label strategically, both as a resource and as something to be incorporated into their identity, depending on the extent to which they think it benefits or harms them in different realms and specific situations (Beard and Fox, 2008; Beard, 2016). 'Awareness' is a highly complex, value laden, context-sensitive concept (e.g. Cadell and Clare, 2010; 2011; Clare, 2002; 2003; Howorth and Saper, 2005) and it makes little sense to talk about 'acceptance and denial' (Macquarrie, 2005) as people with dementia often oscillate between these standpoints, suggesting a 'pendular' rather than linear trajectory (Beard, 2016).

Writing about AD in particular, Beard and Fox (2008) contend that people are socialised by medical structures and the mass media into adorning the diagnostic label. More recently, Beard (2016) reports that the first step in this process of socialisation, namely receiving a diagnosis, need not lead to the adoption of the 'master status' of 'Alzheimer's patient' and indeed this adoption is neither intuitive nor the predominant reaction. In her extensive study of the experience of and response to receiving a diagnosis of AD in the USA, some people never took the second step of 'accepting' their

forgetfulness as a disease and a small minority rejected the diagnosis explicitly. Beard (2016) theorises that joining an AD support group socialises people into seeing their forgetfulness as a disease and this proves a crucial third step in solidifying the identity of 'an Alzheimer's patient'.

In terms of my interest in 'ordinary doing', literature review found that establishing routines and keeping busy in meaningful activities have generally been discussed as means of coping (e.g. De Boer et al. 2007; Harris 2006). Everyday activity is believed to be meaningful when it provides people with dementia with a sense of social belonging and continuity of identity (Beard and Fox, 2008; Harmer and Orrell, 2008; Menne et al, 2002; Phinney, Chaudhury, and O'Connor, 2007). Helping others has been found to enable persons with dementia to feel useful and that they are making a contribution (Beard and Fox, 2008; Menne, Kinney and Morhardt, 2002). Family identity may be sustained through prioritisation of efforts to continue with activities valued by all family members (Davies, 2011; Genoe et al, 2010; Phinney et al, 2007) and different responses to altered activities by gender have been highlighted (Phinney et al, 2007).

While a few studies have explored how family caregivers promote the person's involvement in everyday activity (Hasselkus and Murray, 2007; Perry and O'Connor, 2002; Phinney, 2006), a small and more recent body of work shifts attention from personhood to 'couplehood'. A systematic literature search by Olivia and colleagues (2016) unsurprisingly found couples vary greatly in their response to dementia, but many were striving to maintain their shared sense of being a couple. While differences in response can result in 'narrative collisions' (Tolhurst, Weicht and Kingston, 2017), partners do not need to react to a diagnosis in the same way to be coping as a couple (Beard et al, 2012) and resistance to the label by the person with dementia was generally understood as a means of coping rather than pathologised as denial (ibid).

Overall, the research has a dominant focus on how people cope and what kind of adaptations people have made in their lives as a consequence of their condition. The importance of contributing and continuing with valued activities for identity is apparent, although with few exceptions, such as Hulko's (2004; 2009) consideration of intersectionality, the complexity of identity is generally overlooked. Importantly, the literature exposes discrepancies between exclusively negative cultural representations of dementia, as discussed in Chapter Two, and the actual lived experience of the persons or couples taking part in the studies reviewed. There is however a lack of research that

suspends assumptions of difference to consider *how* an ordinary, everyday life is accomplished.

Towards Social Citizenship: Broadening the Dementia Debate

Bartlett and O'Connor (2010) cite three main reasons why the dementia debate must broaden. First, one consequence of earlier diagnosis of AD and related dementias is that many people so diagnosed are participating in and contributing to society and an alternative model is needed to reflect that reality. Secondly, there is a need to move beyond the discourse about disease and the emphasis on individual adaptation and coping to address the societal attitudes and barriers that people face. Thirdly, there is a need to introduce a more critical perspective that challenges the assumed homogeneity of people with dementia and considers the influence of multiple sources of privilege and disadvantage on their everyday experiences (Bartlett and O'Connor, 2010:7).

The authors adapt a previous model for contextualising personhood in dementia (O'Connor et al, 2007) to recognise the multiple layering associated with the socio-cultural context and to incorporate the notion of citizenship. In so doing, they draw together the emancipatory ethos and explicitly political orientation of the disability movement with calls from critical gerontology to attend to structural and discursive forces, such as those described in Chapter Two. The resultant conceptual framework is founded on the need to 'move beyond seeing the person as a passive care recipient to seeing a person as an active social agent in the broad context of their lifestyle' (Bartlett and O'Connor, 2010:4). This aspiration aligns well with the overarching aim of the research study.

Modern day citizenship has been concerned with equality, political, civil and more recently social rights, and reciprocal responsibilities (Marshall, 1949/92). While the concept has been used successfully by the physical disability movement, its introduction into other domains has often been accepted uncritically (Johnson and Walmsley, 2010). Grounded in assumptions that citizens have the capacity to make reasoned decisions, assume responsibility and fulfil civic obligations, Bartlett and O'Connor (2007; 2010) stress that this view of citizenship makes it virtually unworkable for dementia studies, adding that what citizenship actually means in relation to individuals with dementia, particularly those who are severely cognitively impaired, remains under-theorised. Their positioning of the framework developed in response to this theoretical gap is encapsulated in the title of the book, '*Broadening the*

Dementia Debate: Towards Social Citizenship'. The book sets out to expand imagination, raise questions, to inform and evoke debate and inspire others to think deeply, rather than provide definitive answers (Bartlett and O'Connor, 2010:129). One of the issues the authors continue to grapple with is the relationship between personhood and citizenship (p127) and this is an issue that I grapple with too. In the discussion that follows, I remain attentive to the type of agent, subject, self, person or citizen in view.

Revisiting beginnings: The social model of disability and cognitive impairment

The social model of disability, first championed in the context of physical disability, has contributed powerfully to arguments for people with impairments to make their own decisions about how to live their lives and what support they need, to advance disability legislation and human rights, and ultimately to be regarded as equal citizens. Over the last 20 years, the model has also been used as a framework for conceptualising cognitive impairment (Bartlett, 2000; Gwilliam and Gilliard, 1996; Marshall, 1998).

There have been 'two waves' within disability studies, which differ in emphasis and aims (Bartlett and O'Connor, 2010:8). The first wave exposes and examines problems in society. It views disability as a form of oppression and is committed to assisting people with impairments to fight for full equality and social inclusion. This model, first proposed by disability researchers such as Oliver (1996), severs the casual connection between bodily impairment and disability, thus diverting attention away from the impairment and from experiences of impairment. The model has been critiqued (e.g. Corker, 1999; French, 1994; Thomas, 2004) for being dominated by the concerns of physically disabled, educated, white, young men, and ignoring people with disabilities from marginalised groups. Moreover, care has often been depicted as demeaning and oppressive, reducing people in support roles to technological aids (Meyer et al, 2007), thus contributing to the devaluation and marginalisation of care (Johnson and Walmsley, 2010; Barnes, 2011).

Such critiques have given rise to a second wave of disability scholars who emphasise the interactions between people with impairment and social locations. They do not sever the causal connection between bodily impairment and disability, as this is seen as denying the daily realities of people with impairment and those who care for them (Barnes et al, 1999; Thomas, 1999; 2004). Moreover, they recognise that impairments are likely to matter for wellbeing and life projects no matter how accommodating the

social response (Nussbaum, 2006). The extent to which the barriers to full societal participation can be reduced when the impairment is cognitive rather than physical is contestable (Chappell, 1997; Shakespeare, 2006). It is the understanding embedded within the second wave that been taken forward within dementia research (Bartlett, 2000).

The introduction of the concept of disability has been helpful in moving dementia theorising into the realm of the social, posing questions about the relationship with the wider environment, particularly the influence of the social and built environment in enabling or disabling people with dementia (Marshall, 1998). Importantly, viewing dementia as a disability also encouraged a focus on remaining abilities instead of losses and stressed the importance of attending to personal experiences of dementia (ibid). This triggered the adoption of more emancipatory approaches to research seeking to change the situation of people with dementia, with many researchers seeking to meaningfully include participants with dementia and employing innovative methods to achieve this (Wilkinson, 2002).

Although holding potential to increase awareness of the ways in which people with dementia are discriminated against or marginalised, initial applications of the social model of disability were limited, largely taking the form of a logical extension to the personhood model's relationship between neuro-pathology and the interactional environment. This limited reach has been attributed to the apolitical nature of 'personhood' that continued to anchor dementia studies (Bartlett and O'Connor, 2007).

Adopting the language of rights: Abandoning care?

One problem attributed to the notion of personhood is that it can lead to needs-based language, positioning the person with dementia as a care recipient. In contrast, rights-based talk repositions the person with dementia as a citizen and assumes legitimacy and value (Bartlett and O'Connor, 2010:63). Rights have important symbolic as well as judicial value, and in a society where independence is valorised, can enable people to give, seek and receive care without this being perceived as burdensome (Barnes, 2012). However, the downside of the adoption of a more overtly political vocabulary is that it can devalue care or render it invisible (Barnes, 2011). Care ethicists have argued that a focus on rights alone is incapable of addressing the 'situatedness of human needs or the relationality of processes through which needs are met' (Sevenhuijsen 1998:8). This

assertion has been affirmed in the context of dementia studies concerned with long-term care decision-making (Brannelly, 2011a; 2011b).

In Chapter One, I alluded to my professional experiences of working to the personalisation agenda, whereby disability rights-based arguments unfortunately became conflated with consumerist and neo-liberal ideals (Needham and Glasby, 2014). Long-term campaigner, Jenny Morris, has reflected that activists within the Independent Living Movement may inadvertently have provided support for Government aspirations to divest collective responsibility for welfare and wellbeing, with activists' claims for the right to self-determinacy equated with individual responsibility, and independence with freedom from dependency on the state (Morris, 2011). Nevertheless, the moral authority invested in the seemingly progressive rights-based discourse at the heart of personalisation cannot easily be challenged (Needham and Glasby, 2014). Older people with dementia who need care at home have not been well served by the resultant individualised market-based solutions that they have the right to choose between (Hart, 2014).

Conceptualisation of the person in liberal theories of justice: The monologic self

Traditional liberal justice discourse is grounded in philosophical assumptions of rationality, reflection and conscience, relegating those whose reason is perceived to be flawed to the margins (Nussbaum, 2000) or excluding them from the category of person (Kittay and Carlson, 2010). The putatively 'universal' Charter of Human Rights has required the introduction of several additional conventions for traditionally marginalised groups (Johnson and Walmsley, 2010). Despite these often-overlooked limitations, 'human rights' has provided a useful lens to critique the status of older people with dementia. For instance, findings from an enquiry into the treatment of older people in hospitals and care homes in the UK showed some of the areas in which human rights were contravened (House of Commons, 2007), mostly the right not to be ill-treated. Boyle (2008) notes that civil rights accorded can be over-ridden and are often constrained by lack of access to social rights, particularly adequate community services. While the various rights of people with dementia are important and have inarguably been neglected for too long, the limits of a focus on rights alone intimates the need to take a broader view. The notion of citizenship-as-practice offers a more holistic lens.

From citizenship-as-status to citizenship-as-practice

The meaning of 'citizenship' is subject to ongoing scrutiny, debate and development. The founding idea of citizenship as membership or status is problematic, part of a larger dynamic of exclusion and othering (Lawy and Biesta, 2006). Moreover, the compliant yet active citizenship embedded in much contemporary policy discourse is associated with a neoliberal view of the citizen-consumer; a rights holder and claimant, who in turn fulfils his responsibilities and is explicitly concerned with his own interests. The neo-liberal blueprint designates only certain practices and ways of being as appropriate to citizens (Fisher, 2008). While it may be convenient for government to regard citizenship in this way, a more inclusive approach is required. The notion of *citizenship-as-practice*, articulated as an inclusive and relational concept (Lister, 2007), provides a richer framework for elucidating what it means to be a citizen. It is concerned with people's lives, invests in their understandings and agency and does not seek to impose a particular interpretation upon them (Lawy and Biesta, 2006).

Within the context of dementia studies, Bartlett and O'Connor (2010) expand citizenship to include 'social practice,' informed by work of Prior, Stewart and Walsh (1995), in which individuals are understood to relate to their communities and the state through participation in life (rather than through political participation as narrowly understood) and through their everyday talk and actions (Barnes, Auburn and Lea, 2004). Citizenship is thus understood as something that people do, realised through action and in relationship. This idea fits with 'the cultural turn' in sociology, deconstructing tightly structured accounts of social life in favour of more relational and culturally based explanations (Bartlett and O'Connor, 2007:112). Drawing upon such developments, the authors advanced the following working definition of social citizenship, opening the door to the potential application of citizenship to studies of the lives of people with dementia:

'A relationship, practice or status in which a person with dementia is free from discrimination and has opportunities to grow and participate in life to the fullest extent possible' (Bartlett and O'Connor, 2010: 37).

The shifts in understandings of dementia in recent decades suggest possibilities for future change. This is important as it is still early days for the citizenship of people with dementia (Bartlett, 2016), as reflected in the empirical research literature. Upon commencing this study in 2013, there was a relatively sparse body of literature on the subject of 'citizenship and dementia', the majority post-dating Bartlett and O'Connor's

(2007) original article. Perhaps inevitably, the earliest articles and studies embraced issues of social inclusion, rights and responsibilities, such as mental capacity legislation (Boyle, 2008; 2010). This paved the way for applications within institutional care settings, such as the adoption of an 'ethic of care' perspective on citizenship in connection with long-term care, mental health nursing and social work practices (Brannelly, 2011a; 2011b). The corpus has grown in the intervening years and the concept of social citizenship has been used in different ways, such as in relation to the work of dementia activists (Bartlett, 2014a; 2014b) and in conjunction with policy debates in Sweden (Nedlund and Nordh, 2015). Much of the research however continues to be based in public service settings, with a focus on care dyads between service providers and families affected by dementia (Bartlett, 2016).

The growing interest in citizenship and dementia culminated in the publication of a special issue in the journal *Dementia* in 2016 (eds. O'Connor and Nedlund) representing work across two continents. This illustrates a more recent and tentative expansion of the concept into community settings, including an innovative community-based walking programme for people with early onset AD (Phinney et al, 2016), a community arts project (Dupuis et al, 2016), agentic expressions in the beauty salon (Ward et al, 2016) and the possibilities for citizenship afforded by rural and semi-urban spaces (Clarke and Bailey, 2016). What unites these studies is the desire that people might live well with their diagnoses, whether by attending to discriminatory practices or participatory opportunities.

In parallel, concepts emerging from broader citizenship studies continue to be reviewed to ascertain if they might increase the possibilities for the advancement and enactment of social justice in the lives of people with dementia (Bartlett, 2016). This includes refinements to facilitate utilisation in connection with persons whose capacity to be effective citizens is compromised neurologically as well as socio-culturally (ibid). These constructive developments are summarised below before turning to the largely untapped potential of recognition (e.g. Fisher, 2008; Honneth, 2001; McNay, 2008), a vital aspect of citizenship-as-practice (Lister, 2007).

Citizenship and dementia activism

The traditional view of citizenship neglects the influence of social movements (Bartlett and O'Connor, 2010). The notion of citizenship-as-practice in contrast facilitates academic engagement with the significant minority of people with dementia in the

United Kingdom and elsewhere who are uniting in collective action, challenging marginalisation and influencing policy, practice development and societal attitudes about people with dementia (e.g. Bartlett 2014a; 2014b; Clare, Rowlands, and Quin, 2008; MacRae, 2008). Members of groups such as the Scottish Dementia Working Group (<http://www.sdwg.org.uk/>) and Dementia Advocacy and Support International (<http://dasninternational.org/>) are establishing their position as active citizens rather than victims of a disease (Bartlett and O'Connor, 2007). This movement has been highly effective, exerting direct influence on Scottish and UK Dementia Strategies (Department of Health; 2009; Scottish Government, 2010; 2013-2016; 2017).

The group members are ensuring that the next generation of people diagnosed have a richer repository of stories from which to draw and their actions and visibility in the public sphere constitute a counter-movement to the negative culture of previous decades. Bartlett (2014a:641) recognises that one possible risk is that 'people with dementia who are not verbally fluent, visible, mobile and self-confident remain stigmatised and discriminated against'. A nuanced and more fully inclusive approach is required to ensure effective citizenship is meaningful for people with dementia who may not be willing or able to get involved, and for people who are ambivalent about or actively resist the dementia label.

Tremain (2005) adopts a Foucauldian perspective to argue that the social model of disability remains wedded to a repressive conception of power embedded in oppressive structures, calling into question both the largely uncontested object "impairment," as well as overtly political arguments for rights. Specifically, while "impairment" may offer leverage and legitimacy courtesy of medicalisation, often this is at unrecognised cost. It isn't simply that society constrains the freedom of persons with pre-existing impairments, rather, the process of diagnosis and subsequent response constitute freedom in ways that are circumscribed as "impaired". In Foucault's terms, there is a need to attend to productive as well as repressive forms of power. This observation seems particularly pertinent in the case of older people labelled as impaired as the result of a politically motivated push for early diagnosis, and where the cost is often apparent. It speaks to Davis' (2004) remarks regarding the productive power of the biomedicalisation of dementia summarised in Chapter Two. Tremain (2005) goes further however, suggesting that as the ascribed identity must meet the requirements of certain social and political arrangements, social movements that ground entitlement in that identity will ultimately extend those arrangements.

I find Tremain's perspective thought-provoking, particularly as many dementia activists are not only more able and articulate, but are also considerably younger than the majority of people with dementia, concluding that much will depend on what is being campaigned for. Bartlett (2014b) has identified three emergent modes of dementia activism, with people motivated to campaign to protect the self against decline, (re) gain respect and create connections with other people with dementia. This emphasises a distinctive feature of dementia activism, namely temporality. Bartlett (2014b) draws upon Carstensen's (1995) socioemotional selectivity theory to suggest that because time was perceived as limited by the study participants, they privileged emotional goals and campaigned for equality and respect as opposed to a stake in knowledge production. Moreover, as reported separately, the activists experienced emotional fatigue due to non-conformance with expectations about what people with dementia should be like (Bartlett, 2014a).

Bartlett's (2014a, 2014b) findings take me back to the issues that first motivated this study, notably the discounting of stories that depart from the dominant cultural representation, as encountered on national television, in practice settings and in ordinary social life. They underscore the importance of recognition of and respect for differences in a person's response to and lived experience of dementia. Responses may range from quietly embracing the diagnosis, embarking on a pendular trajectory of acceptance-and-denial, preferring to think of cognitive dysfunction as part of ageing, or actively campaigning for equality.

As Bartlett observes (2014a), her study raises important questions about what effective citizenship means for people with dementia who are unable to contribute in this way, and I would add, who may be highly motivated to contribute to social life in other ways. Three notable developments seeking to further extend the applicability of a social citizenship value lens are: 1) the expansion of citizenship into the realm of the ordinary in dementia studies; 2) calls for a narrative citizenship for people with dementia and 3) the focus on recognition as a vital aspect of citizenship. Each is discussed in turn.

Stepping into the Ordinary

As intimated above, the majority of research articles addressing citizenship and dementia focus on care relationships between service providers and families affected by dementia, often set within public service settings. Recently, Bartlett (2016) has sought to expand the utility of social citizenship for dementia studies by drawing upon

a particular development in citizenship studies, namely an understanding of citizenship as occurring in ordinary places, relating this to the development of Dementia Friendly Communities. This step into the ordinary includes both ordinary citizens, understood as people who are not politically engaged, and ordinary places, defined as 'mundane spaces of daily sociability', such as buses, parks, bars and cafes (Neveu, 2015:147).

Neveu (2015:147) suggests that these 'mundane spaces' have political potential because they provide opportunities for 'subject positions to be experimented with and relations transformed'. She argues that approaching citizenship processes 'from the ordinary' is a fruitful perspective, which can render otherwise unseen barriers to participation and growth visible and from which the political dimensions of usually unseen or unheard practices and sites can be grasped (Neveu, 2015:141). What is 'rendered visible' is not only 'daily, hardly visible resistances', but also 'established configurations and representations that often frame our gaze and forbid us, as researchers, to critically explore them' (Neveu, 2015:150). This attention to the unseen and unheard practices and barely discernible resistances of ordinary social life was something that I identified as a gap in the dementia literature when I commenced the study, and something that I sought to 'render visible'.

Bartlett's (2016) account of 'the ordinary' face of citizenship was published as I neared the end of the study, together a few articles more directly concerned with ordinary people in ordinary places, albeit generally mediated through community projects (e.g. Phinney et al, 2016; Ward et al, 2016). Of particular note is the study by Clarke and Bailey (2016) which explores everyday life with dementia in rural and semi-urban settings and asks whether people with dementia feel on the inside or outside of physical places. The authors depict citizenship as co-constructed through everyday practices that take place between people with dementia and their social and physical environments, and manifest in the stories they tell of belonging (or not) in a social and physical place. In so doing, they draw upon Baldwin's (2008) 'narrative citizenship', a notion which first alerted me to the possibility of exploring the relationship between narrative and everyday practices, and of engaging methodologically with the 'ordinary doing' (Hughes et al, 2006) of everyday life as lived.

Narrative Citizenship

Baldwin (2008) makes an important contribution to the advancement of citizenship in dementia studies, responding to Bartlett and O'Connor's (2007) discussion paper by

bringing together narrative and citizenship and calling for a 'narrative citizenship that is given structural and organisational form' (Baldwin, 2008:223). He observes that citizenship relates to our own existence, our sense of belonging in and contributing to society and thus '[t]he legal, political, and social rights of citizenship are embedded in social relationships and everyday activities' (Powell and Edwards, 2002 in Baldwin, 2008:224).

Baldwin (2008) questions the rigid distinction between personhood and citizenship, offering a performative understanding of personhood. He asserts that we are narrative beings and that the personal and political are connected through the stories we tell and told about us. In so doing, he alludes to the constitutive role of narrative and introduces the idea of the dialogic self, namely the inter-subjectivity of self and Other, with 'Other' expanded to include both interpersonal and institutional Others. Finally, he observes that collective narratives such as policy narratives define the space in which individuals exercise their citizenship rights and identities can be legitimately performed, adding that these spaces may not be the ones that individuals would choose (Baldwin, 2008:224). Baldwin (2008) goes on to underscore the importance of countering meta-narratives, such as the cultural narrative of loss. Consistent with a performative understanding of personhood, he states that to challenge disabling meta-narratives, counter-narratives that are individual, enabling and meaningful need to be both constructed and realised (Baldwin, 2005:1027).

Although connecting narrative with the everyday social practices of citizenship, Baldwin (2008) focuses primarily on the stories we (try to) tell and that are told about us. This is consistent with his commitment to highlighting and countering the 'narrative dispossession' of people with dementia and maintaining the person with dementia's narrative agency as far as possible. Clarke and Bailey (2016) similarly apply the concept to engage with citizenship practices as manifest in the stories people with dementia tell. My interest in 'ordinary doing' steered me in a different direction. Finally, drawing from Plummer's (1995) *sociology of stories*, Baldwin (2008:25) discusses the constraining force of 'stories in the wider world', whereby some voices are capable of framing the questions and setting the agendas, restricting the stories that can be heard. This reminds me of Bender's (2003) observation that the framing of research questions may unwittingly contribute to the perpetuation of assumptions of difference, as described in Chapter Two.

Baldwin's (2008) ideas have far-reaching implications, both for people who may become 'narratively dispossessed' as a result of an inability to tell a verbal story and, of particular interest to this study, for people who wish to narrate accounts, and indeed live lives, that conflict with dominant cultural representations but nevertheless exist 'within the domain of the possible' (Taylor, 2008:324). The relationship between narrative and the everyday practices of citizenship, narrative and life is explored in detail in Chapter Four. I begin to expand upon Baldwin's (2005; 2008) ideas in the remainder of this chapter by looking more closely at the notion of the relational, dialogic self and the human need for recognition. I then establish the place of recognition in a relational and inclusive understanding of citizenship-as-practice suitable for dementia studies.

The Politicisation of Recognition

The Hegelian concept of recognition is implicit in Kitwood's (1997:8) definition of "personhood" – 'it implies recognition, respect and trust'. In recent years, theories of recognition have assumed an overtly socio-political orientation. Recognition is premised on understandings of subjectivity as dialogic, generative and situational (McNay, 2008:4) whereby individuals come to understand themselves only through and in relation to others. The self, whether an excluded subject or a moral agent, is generated through ongoing engagements with the world, and these embodied practices are materially, socially, culturally and historically mediated (McNay, 2008). As such, agents acquire their moral identity through their everyday practices (Sevenhuijsen, 1998:56). These theories challenge the foundational assumptions of Western liberal philosophy and present different ways of conceptualising what makes for a good life (McNay, 2008).

Recognition theorists deal, in slightly different ways, with questions of social and political justice and the injustice resulting from withholding recognition and claims of identity. Honneth (2001) contends that we need to feel cared for and loved in our intimate relationships (self-confidence), appreciated by our community, (self-esteem) and respected as equal in society (self-respect) to build and maintain a positive identity throughout our lives. He holds that our dependence on inter-subjective recognition is institutionalised in society in three spheres of life, the family in the private sphere, work in the public sphere and equality in law and status in the legal sphere (ibid). In all three spheres, the establishment of one's self-understanding is inextricably dependent on recognition by others and all three types of recognition lead to human beings enjoying dignity and integrity. Honneth

(2001:50) describes integrity as 'individuals' ability 'to rest secure in the knowledge that the whole range of their practical self-orientation finds support within society.' While the importance of equality in law and status has received attention in dementia studies, other sources of recognition remain largely unexplored.

Violations of recognition patterns, withheld recognition or forms of disrespect can be viewed as distortions of the good life. Honneth (2001) is concerned with pointing out the disruptions, pathological distortions, everyday troubled identities and experiences of humiliation, suffering and injustice, ranging from the relatively harmless case of not greeting someone to the serious case of stigmatisation. The task is 'to elucidate and diagnose social pathologies', where pathologies are developments in society that are 'wrong' rather than simply unjust (Honneth, 1996:370). He contends that this elucidation must relocate its analysis in the structural conditions of reciprocal recognition. His work thus introduces possibilities for extending considerations of the malignant social psychologies that Kitwood (1997) sought to expose and rectify in institutional care settings to the social pathologies in societal institutions. These possibilities have been enriched through feminist revisions and particular empirical applications, as discussed below.

'Misrecognition' is empirically evident in a range of exploited, excluded and oppressed groups' collective identity claims and claims for difference. Such claims have been the subject of extensive discussion (e.g. Fraser and Honneth, 2003; Taylor 2004; McNay 2008). Of particular interest to this study, Fisher (2007; 2008) has considered misrecognition experienced in health settings and care encounters. She highlights a particular form of misrecognition that occurs when people are measured according to normative frameworks, based on ontological separatism. Bolstered by biomedical models, they connect difference and individual deficiency (Fisher, 2008). This speaks directly to my motivating concern about post-diagnostic support encounters between practitioners and older people with dementia, but as outlined in Chapters One and Two, the influence of biomedicine is pervasive, seeping into policy, the media and the lifeworld (Manthorpe and Iliffe, 2016). The potential for misrecognition in the course of 'ordinary doing' appears significant.

Human recognition is understood as a precondition of agency. Needs for love, appreciation and respect do not disappear as we age and may become even more urgent when people lose their functional abilities and become more dependent on others. While

misrecognition is likely to undermine agency, people may be prompted to resist¹⁰ in myriad ways, whether by constructing counter-cultures such as dementia activism (Bartlett, 2014a), counter-narratives as encouraged by Baldwin (2008) or the barely discernible resistances of ordinary people engaged in ordinary doing in ordinary places that Neveu (2015) seeks to render visible. Diverse forms of resistance and sophisticated forms of agency have been testified by a number of qualitative studies conducted with so-called vulnerable groups (Black, 2009; Charmaz, 1999; Fisher, 2008; Wheeler, 2005). Fisher (2008) has noted how resistance among socially marginalised groups can trigger alternative articulations of citizenship that challenge neo-liberal models emphasising individual autonomy.

Recognition has been identified as an important aspect of inclusive citizenship (Lister, 2007:51). Given the growing diversity and expectations of men and women with dementia, it follows that there are many different ways of practicing and realising social citizenship (Bartlett, 2016). Following Fisher's (2008) line of argument, the quest of people with dementia to construct positive understandings of the value of their lives may be impeded or halted by forms of misrecognition that position them as inferior and vulnerable to patterns of disrespect, and those that fail to appreciate their particularities and distinctive contributions, impacting on self-esteem.

Fisher (2008) also calls attention to Arendt's (1998) differentiation between 'who' a person is and 'what' she is. 'What' refers to capabilities and labels that may be attributed externally and may be subject to comparison. 'Who' a person is refers to more intangible and unique qualities, which cannot be predicted or controlled, only revealed through speech and action. To define a person according to membership of a single group, such as a person with dementia, is to deny the complexity of human identity. Fisher (2012) asserts that this is why qualitative studies should seek to reveal rather than to erase the complexities of identity, adding that the framing of identities within qualitative studies can either open up or close down possibilities for complex and radical self-representations. She warns of the danger of constructing the identities of socially marginalised people as necessarily embedded in forms of suffering. Studies should also remain alert to the possibility that social suffering may prompt radical forms of resistance (ibid). These remarks, coupled with Neveu's (2015) attention to the

¹⁰ I heed Hoggett's 2000 warning that it is important not to conflate agency with resistance or reduce agency to constructive coping

barely discernible resistances of ordinary life, had a significant bearing on my thinking about how best to frame the research questions and upon the study design.

Dismantling the public - private divide

Honneth (2003:141) has asserted that 'achievement' is located in the 'public' sphere and measured according to '[a] value standard whose normative reference point is the economic activity of the independent, middle-class, male bourgeois'. In so doing, his concern is to identify contemporary social pathologies that disrupt this traditional source of recognition. Fraser and Owen (2008) critique the notion of ideal citizenship as associated primarily with activity in the 'public' domain rather than the 'private'. They build on previous analyses grounded in an 'ethics of care' to challenge normative notions of citizenship based on economic self-sufficiency (Fisher, 2007; Kittay, 2001; Sevenhuijsen, 1998; Williams, 2001). Care ethicists assert that this distinction itself is an ideological construct, based on highly gendered and also ageist assumptions that define some forms of participation and contribution as legitimate and exclude others (Fraser, 2008). For example, Skeggs (1997) found that working class women often reject a contractually based 'rights and responsibilities' agenda and gain a positive sense of self through appearance and domestic and caring activities. In the absence of other opportunities, this 'corporeal generosity' (Diprose, 2002) was highly valued as a form of cultural and emotional capital. I suggest that there is scope to extend considerations of alternative forms of 'achievement' to dementia studies in general and particularly when engaging with the 'ordinary doings' of older people with dementia.

Bartlett (2016) also observes that what happens inside and outside the home is inevitably intertwined and politicised for many people living with dementia. While she is concerned with the absence of discussion about the micro-injustices faced by people with dementia within the home, care ethicists, in this respect, are keen to replace narrow, gendered accounts of achievement as confined to the public sphere. Entering the private sphere thus holds potential to render visible previously hidden forms of misrecognition and discrimination as people go about their everyday lives.

The Place of Care in Citizenship

The 'ethic of care' has been referenced in this chapter in a restricted way, notably to highlight the limits of a focus on rights alone and to challenge gendered assumptions about the public: private divide. More broadly, care ethicists make what I consider to be a compelling case for care to be valued and deemed necessary for citizenship and social

justice. Specifically, the ethic of care provides a framework for sustaining citizenship in the context of the situated and often difficult circumstances of care (Tronto, 1993), where care is broadly defined. The framework is based on the acceptance of human interdependencies. It calls attention to the need to handle the embodied nature of humanity and how this intersects with our own emotional responses to the processes of ageing and impairment (Barnes, 2012).

The ethic of care literature has grown considerably over the past thirty years from its early considerations of care as a private, devalued and highly feminised practice to engage with care as a political value and set of sensitising principles. These principles of attentiveness, responsibility, competence and responsiveness (Tronto, 1993) and trust (added by Sevenhuijsen, 1998 as both a condition for and outcome of care) give ethical content to four interconnected phases of care, all of which must be present if care is to have integrity: caring about; taking care of; care giving and care receiving. The framework has been used to guide assessments as to whether diverse types of relationships, practices, processes of decision making and policies meet or are capable of enabling the conditions in which we can all live well (or as well as possible) individually and together (Barnes, 2012). Its application requires deep knowledge of the particularities of the situation. Although not seeking to apply the framework to the research study's core interest in 'ordinary doing', in Chapter Nine I utilise the ethic of care principles to evaluate the research relationships with the study participants.

Reflections and Way Forward

Having uncovered a growing interest in the 'ordinary doing' of everyday life across various disciplines in Chapter Two, my research interest in 'the ordinary' was reinforced by a persistent plea for 'ordinariness' from people living with dementia when I reviewed the empirical dementia literature. I found further encouragement to progress this interest through recent developments expanding citizenship practices into the realm of 'the ordinary', encompassing 'ordinary citizens' and 'mundane spaces of daily sociability' (Neveu, 2015).

The literature review also established the place of recognition in a relational, inclusive and nuanced understanding of citizenship-as-practice. Expanding Fisher's (2008) arguments to dementia studies, the quest of people with dementia to construct positive understandings of the value of their lives may be impeded or halted by forms of misrecognition which position them as inferior and vulnerable to patterns of

disrespect, and also those which fail to appreciate their particular contributions, impacting on self-esteem. In addition to my earlier concerns about framing the research questions in a way that might inadvertently reinforce assumptions of difference, I now take cognisance of Fisher's (2012) observations, aspiring to preserve the complex, dialogical nature of identity.

Further, the emphasis on practice within the citizenship literature in general and on the performative in 'narrative citizenship' (Baldwin, 2008) helped shape my methodological thinking, stimulating my desire to engage directly with action, interaction and the 'ordinary doing' of everyday life as lived. I also sought to better understand the relationship between narrative and the everyday practices of citizenship. Baldwin's (2008) account of 'narrative citizenship' provided clues as to how this might be possible.

Discovering narrative-in-action

Acting on the above clues, I purposefully expanded my search of empirical studies beyond the dementia literature. I sought to develop a broad understanding of potential methodological approaches that would facilitate engagement with the situated nature of everyday activities and the enactment of everyday practices of citizenship, and then assess the likely utility of these approaches in a study involving older people with dementia. My search led me to the 'narrative-in-action' methodology (Alsaker, Bongaardt and Josephsson, 2009; Alsaker and Josephsson, 2010; 2011; Alsaker, Josephsson and Dickie, 2013), a form of Narrative Inquiry, which introduces both theoretical and methodological possibilities for engaging with the meaning-making processes inherent in everyday activities.

Alsaker and colleagues (2013:66-67) recognise that everyday life comprises numerous and diverse activities, but 'the pace, the meanings, the shifting and overall variety that characterise everyday activities and the interplay with place, condition and sociality are difficult to grasp'. The significance of formerly unnoticed activities becomes apparent when the ability to perform them is compromised. As a result, once taken-for-granted and even mundane activities assume altered values, not simply on account of performance abilities, but according to meaning-related issues (ibid).

Alsaker and colleagues (2009) developed the methodology to facilitate a study with women with chronic rheumatic conditions, but they share my concern that research tends to focus on subjective experiences of disruption and what kind of adaptations

persons have made, rather than suspending assumptions of difference and asking how everyday life is lived. Extending their thinking to the experiences of people with dementia, the 'how' focus acknowledges persons with dementia as one facet among many in a varied population, with varying 'ordinariness'. Instead of focusing on the meaning of dementia or difference in the performance of everyday activity with and without dementia, research would ask how a person living with dementia makes meaning in and through these activities. In view of this, together with the insights distilled through my engagement with the literature, I refined the overarching study aim *to explore how 'ordinary' everyday life is accomplished through a social citizenship value lens*.

The narrative-in-action methodology offers provisional resources to engage with meaning-making in action in the form of Ricoeur's (1984) early narrative theorising combined with ethnographic methods. I discuss the theoretical underpinnings of this methodology in Chapter Four, then engage more deeply with Ricoeur's (1992) narrative hermeneutics in order to facilitate the study of dialogic, dynamic and complex identity configurations that encompass the human need for recognition.

Chapter Four

The Bridge: Narrative Theory

Overview

In this chapter, I describe the narrative theories that underpin this Narrative Inquiry and conclude by defining the research questions. The chapter constitutes the bridge between the issues identified through literature review, as summarised in Chapters Two and Three, and the methodological approach taken in conducting the study, which I detail in Chapter Five. Specifically, in order to address the study's aim of exploring how everyday life with dementia is accomplished through a social citizenship value lens, I find theoretical support to engage with possible tensions between pleas for ordinariness from older people living with dementia and the increasing biomedicalisation of later life through the meaning-making processes inherent in everyday activities. I also find support to engage with the complexities of identity and the human need for recognition.

Narrative Inquiry refers to a subset of qualitative research designs used to describe human action. The term *narrative* has been employed equivocally by qualitative researchers. In the context of Narrative Inquiry, narrative is recognised as the linguistic form uniquely suited for displaying human existence as situated action. Using narrative theory, the narrative analysis is an attempt to understand persons, including their spontaneity and responsibility, as they act in the concrete social world (Polkinghorne, 1995). This Narrative Inquiry utilises narrative theorising in a distinctive way, namely to engage with participant meaning-making processes in the flow of action and over time, as well as the more customary guiding of narrative analyses, as set out in the sections that follow.

I begin by describing the backstory and how, upon entering the field, I identified the need to expand upon the theoretical underpinnings of narrative-in-action by engaging more deeply with Ricoeur's (1984, 1992) phenomenological hermeneutical philosophy. I then explore the connections that Ricoeur makes between action and narrative and how these connections are affected by temporal and cultural influences. I suggest that Ricoeur's (1984) depiction of narrative as embedded in action and his sophisticated elaboration of the relationship between narrative and life can facilitate a multifaceted

understanding of the person engaged in the 'ordinary doing' of everyday life, both within a given acting situation and over time.

Attending closely to Ricoeur's (1992) articulation of the mediating role of narrative in the construction of identity, I illustrate that this holds significant promise to consider identity implications for older people living with dementia, in all their complexity, as they negotiate opportunities for and obstacles to participation and contribution in ordinary social life and seek recognition. I also draw upon specific insights from narrative gerontology and respond to the challenges that narrativity can present in the specific context of dementia research. In so doing, I underscore the potential to expand important arguments that promote the 'narrative citizenship' (Baldwin, 2008) of people with dementia. Finally, I set out the research questions for the study and summarise the key methodological implications of the Narrative Inquiry, which are then explicated in Chapter Five.

The Backstory

As alluded to in Chapter Three, I came upon the theoretical perspectives set out in the first part of this chapter as a result of a search for empirical studies that engaged with the situated nature of people's everyday activities. Alsaker et al's (2009) '*narrative-in-action*' combines ethnographic methods of data collection with Ricoeur's (1984) ideas about meaning-making in everyday action from his writings on *mimesis*. The authors illustrate its application by considering the everyday activities and experiences of women with chronic rheumatic conditions. The authors' concerns about the consequences of diagnostic labelling and tensions with the wish for ordinariness from people so-diagnosed resonated strongly with my own conclusions as result of my engagement with the dementia literature.

At the point of discovering this approach, my thinking was explicitly socio-political in orientation. I was excited by the ways in which studying narrative-in-action might provide access to the "hows" as well as the "whats" of meaning-making and, as discussed in Chapter Five, I identified several possible advantages of using the advocated ethnographic methods in conjunction with *mimetic theory* with older people with dementia. But I was equally seduced by the findings. The studies showcased the potential to understand personal meanings in light of biomedical discourses and contemporary local cultural contexts.

However, when I first entered the field I found that my encounters with the participants had a rather different feel to them. Their activities generally took the form of the recounting, enactment and undertaking of responsibilities and commitments not only to contemporaries, but also to successors, absent friends and predecessors. The plea for ordinariness that I'd anticipated was made, but the 'ordinary doings' of everyday life were framed within a quest for the good, which ultimately related to laying claim to having lived a good life, whatever happens next. The participants were reading cultural texts as anticipated, but were often somewhat more concerned with 'reading their lives' (Randall, 2008) even in the midst of doing everyday activities. Running through this was the fragile thread of temporality and its unavoidable intertwining with memory and imagination.

Clandinin and Connelly (2000:50-51) highlight that a narrative researcher always finds herself situated in a three-dimensional inquiry space, so that she is in a particular place and that work involves moving 'in and out' from the inner world of the narrator to the wider socio-cultural realm and 'back and forth' in time. It was this 'back and forth' movement that dominated and the emphasis placed on the role of luck, contingency and happenstance across the life course also took me by surprise. I appreciated that to ignore this temporal dimension would, somewhat ironically, be tantamount to a form of misrecognition. I was mindful of Fisher's (2012) observation that researchers should seek to reveal the complexities of participant identities. To avoid closing down possibilities for complex, authentic self-representations, I had to go deeper into Ricoeur's theorising and also engage with narrative gerontology. I had to exercise, with some discomfort, my wholly undeveloped philosophical imagination. The theoretical perspectives set out in this chapter, and that later serve as interpretive tools, are the result of this deeper engagement.

Ricoeur's Phenomenological Hermeneutical Philosophy

Before summarising the essential elements of Ricoeur's (1984; 1992) account of the connections between narrative and life, I think it is important to say a little about the man and his work. Paul Ricoeur was a French philosopher whose publications span nearly six decades from the latter half of the twentieth century. Ricoeur made a major methodological shift during his career, expanding his early work in the tradition of existential phenomenology (put simply, the study of consciousness and the objects of direct experience) to combine phenomenological description with hermeneutic

interpretation. He identifies engagement with and experience of the physical world as prerequisite to attempts to interpret and understand, asserting that meanings are not given directly to us, and that we must therefore make a hermeneutic detour through the symbolic apparatus of our culture (Ricoeur, 1992:197). The hermeneutic tradition emphasises that human existence ‘in itself’ involves a process of constant interpretation and meaning-making. Consistent with accounts of the dialogic self, as set out in Chapter Three, throughout his work, Ricoeur attends closely to our relational as well as our embodied nature and questions the privileged place of reason in understandings of personhood.

The turn to narrative

Ricoeur witnessed the use of power to disenfranchise whole populations of their basic human rights and dignity. As a precociously bright, studious and deeply religious young man, he endured the horrors of World War II, first as a soldier in the French army and then as a prisoner of war in a German concentration camp for five years (Hall, 2007). The volumes that I primarily draw upon (*Time and Narrative I* and *Oneself as Another*) reflect Ricoeur’s interest in the ways that our previous experiences shape our comprehension of the world. Part of this interest was a drive to understand what narrative theory lends to self-understanding (Hall, 2007) and how narratives can be used to influence our beliefs and behaviours so that we might develop the necessary tools and understandings to challenge their misuse. I regard the focus on enhancing ‘narrative citizenship’ (Baldwin, 2008) in dementia studies as consistent with this drive, and find in Ricoeur’s thinking several ideas with considerable potential to progress this particular agenda, as summarised below.

Navigating a course from ‘ordinary doing’ to ‘the aim of a good life’

In the following sections, I follow the overall trajectory of Ricoeur’s thinking from everyday activity to the ethical aim of a good life through the construct of narrative identity. I begin with my interest in understanding situated everyday activity and consider the spiral relationship that Ricoeur (1984:54-78) establishes between action and narrative through his process of ‘threefold *mimesis*’. I suggest that this process may be instructive when exploring situated activities and the ‘small stories’ of everyday events, and may constitute a provisional resource for engaging with people’s unfolding narratives. To develop this capability further, my attention then shifts from practical understanding to self-understanding through the construct of ‘narrative identity’ (Ricoeur, 1992).

Narrative identity underpins narrative citizenship and has far-reaching implications, both for people who may become 'narratively dispossessed' (Baldwin, 2008) and for people who wish to tell stories that conflict with dominant cultural narratives, but nevertheless exist 'within the domain of the possible' (Taylor, 2008:324). Its conceptualisation therefore requires careful deliberation. I then reconnect with the acting and suffering agent at the level of practical life. I review Ricoeur's (1992:153-163) extended account of social action through the introduction of and two-way movement between the nested levels of praxis, namely 'practices', 'life plans' and the practical ideal of the 'narrative unity of a life'. Finally, I move from self-understanding to self-esteem through considerations of the relationship between self and Other and the aim of a good life. I suggest that these concepts may be instructive in interpreting the ways in which disparate activities and events are incorporated into the unfolding narratives of older people living with dementia and shape the future possibilities for participation that they consider, actualise, discount or are denied.

The Relationship between Practical Life and Narrative

The relationship between practical life and narrative emerges from Ricoeur's investigations into time, history and narrative in *Time and Narrative* (1984-1988). It is worth considering this backdrop because it establishes some important concepts that frame aspects of his theory of direct relevance to the study, particularly with regard to identity and the temporal dimension of the self, which is essential to his reflective philosophy. Through this body of work, he considers the divergence between cosmological and phenomenological notions of time. Rather than formulating a convincing, non-circular theory of time that integrates both dimensions, Ricoeur (1984:52) sets out to show that the failure of systematic approaches to the '*aporias*' of temporality is inevitable. Instead he first entertains the idea that there is a correlation 'between the activity of narrating a story and the temporal¹¹ character of human existence' that constitutes 'a trans-cultural form of necessity'. He then advances the following hypothesis:

'Time becomes human time to the extent that it is organized after the manner of a narrative; narrative, in turn, is meaningful to the extent that it portrays the features of temporal experience' (Ricoeur, 1984:52).

¹¹ Davis (2004) critiques Tom Kitwood's work for trying to preserve personhood-without-memory by drawing upon Heidegger's phenomenological perspective on Being-in-Time and temporality. Although outside the scope of this discussion, given the importance attached to temporality in this study, in Appendix XVI I summarise Ricoeur's (1992:319-329) critique of Being-in-Time, which concludes that the phenomenology of spatiality does not receive the attention it deserves.

To demonstrate this correlation, he introduces a process that he calls threefold *mimesis* (Ricoeur, 1984:54), which I describe below. Before doing so, it is noteworthy that it falls to narrative to bring together the two dimensions of time: where philosophical and scientific approaches cannot generate a *proper* solution to conceptual antinomies, we have to look to metaphors or narratives (Teichert, 2004:118 [italics added]). *Mimesis* is the Greek word for imitation. In using this term, Ricoeur (1984) draws upon Aristotle's notion that 'art' (here broadly understood) is a poetic imitation of action and life. Narrative is thus a poetic solution – a poetic imitation of action and life, rather than an exact copy. Ricoeur sees narrative as deeply rooted in life, but this does not mean that life should be equated with story (Verhesschen, 2003).

Action, narrative and the process of threefold mimesis

The concept of triple *mimesis* sets out different levels of meaning-making and the ongoing intertwining of personal, cultural and historical narratives. *Mimesis1* is the narrative *prefiguration* of action and life. Ricoeur (1984) claims that our ability to understand fictional and historical narratives is based on the way that our everyday activities and lives are narratively prefigured, and that the ways we understand each other in daily life involve an irreducible narrativity. *Mimesis1* concerns those aspects of action that have a pre-narrative quality and is the means by which acting and suffering rise to meaning at a descriptive, pre-reflective level within a particular situation. Ricoeur (1984:55-56) identifies three points of narrative anchorage in the world of action. The first point of anchorage is our familiarity with the '*semantics of action*' itself. In essence, narratives presuppose our ability to understand features of action structure such as 'agent, goal, means, circumstance, help, hostility, cooperation, conflict, success, failure etc.' When we describe a particular event, we use narrative's structural elements. In addition, certain discursive features are added that distinguish a narrative from a simple sequence of action sentences. Narrative comprehension therefore presupposes a familiarity with the rules of composition that govern the diachronic order of a story.

The second point of anchorage lies in the '*symbolic resources of the practical field*' (Ricoeur, 1984) and is concerned with the public character of symbols or shared meanings. 'If, in fact, human action can be narrated, it is because it is always already articulated by signs, rules, and norms' (p57). Signs and symbols are representations from a given culture. 'The term 'symbol' further introduces the idea of a rule... in the sense of a norm' or 'what we ought to do' (p58). This suggests that we and others can

evaluate our actions as good or bad, which is of particular relevance to the study's concern with normative assumptions and the risk of misrecognition. Once the symbolic values of our culture are acquired, we intuitively know how to navigate through them through the development of practical understanding (p61).

The skilfulness of practical understanding increases with experience, connecting experience to the final point of anchorage, time. In order to be able to understand an action, the ability to recognise temporal structures in action is also presupposed. He is not overly concerned with the 'all too evident correlations' between projects and a future orientation, actions that draw upon acquired dispositions and past experiences, or the sense of 'I can', 'I do', 'I suffer' that we spontaneously associate with the present (p60). Rather, he calls our attention to the way in which the actual doing of action *within time* orders the 'present of the future, present of the past and present of the present' in terms of one another. Ricoeur (1984:59) argues that we experience time narratively and in his view these temporal features call for narration.

*Mimesis*² is the narrative *configuration* of action, which is a second layer of meaning-making and can be understood as a double hermeneutic; it serves to structure or configure what is already prefigured in action into a unified totality via the operation of 'emplotment' (Ricoeur, 1984:64). Configuration is always a mediator between a need for concordance and the admission of discordance. Emplotment has a mediating function in three ways. First it entails combining or 'grasping together' a series of events into the story as a whole. In this way, a given event takes its meaning, not from itself as a single occurrence, but from the contribution it makes to the story as a whole (Verhesschen, 2003). Second it brings about a synthesis between disparate components like actors, goals, means, circumstances, interactions, unexpected results. Thirdly it mediates between two kinds of time, first an episodic sequencing which suggests not simply that one thing happens after another, but because of the other, and second the creation or configuration of a unified totality (Ricoeur, 1984:65-66).

It is significant that configuration stands outside of the narratively pre-figured field of action as it is this distinction that gives narrative its status as composition or poetic imitation. In addition to ordering and giving meaning to events in the context of a narrative, the mediating operation of emplotment creates the space for considering other possibilities for action, or the kingdom of 'as if' (p64). The plot is not fixed. Events which happened in the field of action can be configured (or reconfigured) in different

ways and assume new meanings. Ricoeur (1984) argues that narrative is the process through which time becomes human because the plots we construct are bound up with the things we care about, our life concerns.

*Mimesis*³ is the narrative *refiguration* of action through the act of 'reading' (Ricoeur, 1984:70-77); it concerns the relation between narrative and temporal experience in that to read is to imaginatively inhabit the temporal world of the text and to be guided by the narrative's horizon of experience. This provides the reader with distance or 'distanciation'. The reader must make the traversal in the same state of imperfect knowledge as those inside the text (Teichert, 2004). Fiction can be a revelation when it calls attention to aspects of experience that we did not notice before, extending an invitation to see the world and ourselves differently (Ricoeur, 1984:72). Moreover, as a narrative is never ethically neutral, it can contain an invitation to act in a different way. Narrative understanding in this sense is practical understanding. This is what Ricoeur (1984) calls the transformative power of narrative. Our transformed experiences in turn will call for narration, and this will lead to different narratives. In Ricoeur's (1984:72) view, the relation between narrative and life is a circular one, preferably regarded as an 'endless spiral' to refute any suggestion that it is a vicious circle. The promise of revelation and transformation may inform studies of narrative citizenship more broadly, notably with regard to the nature and consumption of stories about older people living with dementia (Plummer, 1995 in Baldwin, 2008).

Applicability of Ricoeur's threefold mimesis to the study

Ricoeur's (1984) emphasis on the link between action and narrative via the pre-narrative quality of action offers important insights for the study. In an everyday setting, narratives are not complete with a beginning, middle and end and a clear plot; they are nascent stories (as yet) untold (Ricoeur, 1984:71) or stories in the making. In the course of carrying out everyday activities, people may spontaneously create images from the past or the future, which may be brought together in the acting situation. This spontaneity or the 'simple evocation of a memory that comes to mind' alludes to a different mnemonic phenomenon than effortful recollection through active search (Ricoeur, 2004:29). Older people with dementia have been observed to exhibit different capabilities in this respect in everyday as opposed to clinical test situations (Sabat, 2001) and this distinction may increase possibilities for participation.

Moreover, culture is infused with metaphors (not always pleasant ones, as discussed in Chapter Two) and meanings that the person cannot avoid when acting (Ricoeur, 1984). The person may relate meaning to such possibilities, creating a situational interpretation. Pre-reflective descriptions, triggered memories, imaginings or situational interpretations may then be verbalised and told to a co-participant. Episodic memories, naturally evoked while carrying out everyday activities through the forging of connections to the past are often recounted as stories with dramatic structure (Ricoeur, 2004). Bamberg (2004) also privileges the fleeting and the fragmented, the 'small stories' of the moment as contributing to identity and suggests they resonate more strongly with those whose experience may be more fragmented. Methodologically, being with someone in the flow of everyday activity may present opportunities to access these small stories, plus accounts of past or anticipated events and happenings, partly linked or not linked at all, but embedded in the person's practical actions (Alsaker and Josephsson, 2010).

In addition, Ricoeur (1984) highlights that the pre-narrative quality of action and life does not mean that the plot is always clear. The relation between action and a narrative in which the action gets its meaning is not always obvious (Verhesschen, 2003:455). Emplotment is therefore an important mechanism for bringing together the disparate elements recounted or observed in real-time with the unfolding story of the person's life, and also creating spaces for imagining other possibilities, positive or less positive. I see the different levels of meaning-making set out in the conceptualisation of triple *mimesis* as holding the potential to differentiate my own meaning-making activity in the form of emplotment of research narratives, grasping together various events, happenings and associated meanings, expressed and sense-checked by the participants. This approach has the potential to respect, value and engage with the participants' own situated meaning-making activities, without placing potentially unrealistic demands on them to make connections between events or to remember what they discussed with me over a period of several months.

Finally, Ricoeur's (1984) concept of 'refiguration' lends philosophical moorings to the revelatory and transformative potential of the narratives of people with dementia. I find in threefold *mimesis* important resources for the study, notably recognition of the pre-narrative qualities of action and articulation of the dynamic nature of the relationship between action and narrative in a way that does not simply equate the

two. While this was the extent to which I anticipated using narrative theory within the study, as above, during my early meetings with the participants I experienced a need to connect with the notion of 'having lived a good life'. This connection is forged through the medium of 'narrative identity'.

Going Deeper: The Mediating Role of Narrative in Configuring Identity

Ricoeur (1992) proposes that narrative functions not simply to configure our understanding of our existence, but also structures existence itself. In many ways, what he called the pre-narrative quality of action and experience anticipates the move from narrative understanding to the narrative configuration of identity. The manner in which fictional characters are related to their actions in the construction of the plot offers some purchase on the way in which personal identities are narratively configured in life. Over the course of a fictional story we come to recognise the characters as persons with certain personality traits and ways of dealing with situations and events. The identities of the characters are themselves discrete synthetic entities within the synthesis of the plot (Hall, 2007). They develop as the plot develops:

'The person, understood as a character in a story, is not an entity distinct from his or her "experiences." Quite the opposite: The person shares the condition of dynamic identity peculiar to the story recounted. The narrative constructs the identity of the character, what can be called his or her narrative identity, in constructing that of the story told. It is the identity of the story that makes the identity of the character' (Ricoeur, 1992:147).

Ricoeur (1992) devotes his attention to questions of personal identity and its narrative and ethical configuration in *Oneself as Another*. Engaging with his argument first requires consideration of his account of the person, not as a character in a narrative, but as a human agent in practical life, and how acting and suffering in the world relate to personal identity.

The human agent and competing understandings of personal identity

Ricoeur's (1986) account of the human agent is that of an embodied capability, 'human will' is an incarnate freedom and therefore limited. He recognises the needs, desires, capabilities and fragility of the body, and acknowledges passivity and finitude as part of the human condition (ibid). Human understanding is also located in the perception of the body (Ricoeur, 1986). Ricoeur (1992) makes 'a point always to talk about the human being as acting and suffering' (p145) and uses the term 'suffering' in broadest sense possible, from violence through the inability to control all effects that issue from our actions, to incapacity inflicted on us (ibid). Further, human persons do not only act

and suffer, but also strive to make sense of their own existence and receive affirmation (Ricoeur, 1992). Countering Cartesian accounts of reflexivity, he asserts that the self cannot come to know itself and its world through introspection. Rather, the self comes to know itself through the Other. Selfhood is attested to in the capacity to act in the world and to leave traces on the course of events in the world (ibid).

When considering the identity of the human agent, Ricoeur (1992) engages directly with the confrontation between the two accepted philosophical understandings of personal identity: on the one side, identity as *sameness* over time (*idem*), on the other, identity as *selfhood* (*ipse*) which allows for diversity and change. Sameness refers to both numerical and qualitative identity; to those dimensions of our identity that can be described in third-personal terms, such as our bodily attributes, dispositions, personal values, traits of character and temperament, social roles and so on (Mackenzie, 2008:10). It helps establish permanence of being. Selfhood refers to the first-person phenomenological perspective of an embodied subject, both at a given time and extended over time; to 'the sense of "mineness" or "belonging" that characterizes one's own experiences, memories, body and characteristics' (ibid). The ipse identity is the self that gives humans the capacity to initiate meaning-making interpretations of ideas and experiences that have not been experienced before, and create brand new things. It frames our potential as human beings (Ricoeur, 1992).

Narrative identity: A solution to the problem of identity as sameness and diversity

Ricoeur (1992) argues that personal identity should be understood as both a unification of and ongoing dialectic between the two understandings of identity. He considers personal identity as a practical category: '[T]o state the identity of an individual or a community is to answer the question, "Who did this?" "Who is the agent, the author?"' (Ricoeur, 1988:246). He highlights that the person of whom we are speaking and the agent on whom the action depends have a history and also change through their actions (Ricoeur, 1992). Personal identity can therefore be articulated only in the temporal dimension of human existence. Given the role attributed to narrative in configuring the human experience of time (Ricoeur 1984) it follows that the unity of identity is constituted by a narrative: 'To answer the question "who?" [...] is to tell the story of a life. The story told tells about the action of the "who". And the identity of this "who" therefore must be a 'narrative identity' (Ricoeur, 1988:246).

As with the configuration of time, narrative serves as a mediator between a need for concordance and the admission of discordance (Ricoeur, 1984) in reconciling the temporal dimension of the self. Narrative relates the sameness and selfhood dimensions of identity through the two operations of emplotment, ordering and creativity (Ricoeur, 1992). The ordering function facilitates an understanding as to how someone can remain the same person despite changes in the course of his or her life without the need for recourse to an unvarying substantial self. Creativity allows for future possibility and change through the imaginative space opened up by the fusion of the two horizons. In Ricoeur's (1992) view, selfhood is recognised in its possibility as much as its actuality.

Ricoeur (1992:116-124) concludes by illustrating the dialectic between the two dimensions of identity with the relative terms of character (*caractere*)¹² and self-constancy. Character includes the habits, lasting dispositions and acquired identifications suggestive of sameness, of permanence in time, but which have a history and once required innovation. Self-constancy is a form of initiative that reveals a mode of permanence in time that cannot be inscribed, such as the ability to intend oneself into the future and make good on a promise given in the present. While accounts of character dispositions are not unfamiliar in the dementia literature (e.g. Kontos, 2004), I see new possibilities in the notion of self-constancy. Indeed, this concept chimes with the intuitions alluded to at the start of this chapter, based on my initial engagements with the participants and their aspirations to continue to fulfil commitments, responsibilities and valued roles by intending themselves into the future and resisting ascribed deficient identities. Self-constancy may of course present significant challenges where the capability to lay down fresh memories is impaired. The role of emplotment in creating the spaces for working through future possibilities, or lack thereof, assumes fresh salience in light of this observation, together with the cyclical connection between acting, narrating and seeing possibilities.

The dialogic self: narrative identity, the 'Other' and co-constructed narratives

Ricoeur (1992) attends closely to our social nature, understanding the relation of self and Other as primordial or ontological – we *are* relational beings. As we live with and for others, our identities are the construct of social engagement and demonstrate that we are not independent, but intricately connected with the Other. He provides a rich

¹² Ricoeur (1992) highlights the distinction, often lost in English, between the French terms 'personnage' (character in a novel) and *caractere* (character, qualities or nature of a person)

account of 'Otherness', which encompasses interpersonal relations, institutions and the self-as-other. Our narratives are co-authored and the narrative unification of the self and the Other therefore consists of an identity that exists to be responsive to and act in ways that generate responses from others.

Of relevance to studies of ageing and dementia in general, Ricoeur (1992:180-194) offers an extended meditation on interpersonal solicitude. He considers the scenario where the 'Other' is placed in a situation of vulnerability through an exploration of reciprocity. This account involves others progressively facilitating, holding¹³ and preserving the *ipse* identity of the person as his or her own grasp on it weakens. Additionally, consistent with Baldwin's (2008) account of the dialogic self and the expansion of 'Otherness' to encompass institutions, Ricoeur (1992) acknowledges that living well is not limited to face-to-face encounters, but extends to the life of institutions. Justice presents qualities that are not present in solicitude, notably the requirement of equality. Friends and just institutions are both necessary to protect against suffering and self-destruction.

Ricoeur (1992:320) recognises that there may be some forms of suffering that go far beyond mishaps and adventures which cannot be made meaningful through emplotment. There is scope to enrich this observation with insights from established bodies of literature on selfhood in dementia (e.g. Sabat 2010) which highlight difficulties in reconciling past and present self-understandings. Ricoeur (1992) also insists that narrative identity is not simply descriptive, but requires action and has to reconnect with the non-narrative components in the form of the acting and suffering agent. Ricoeur's narrative theory 'is not a downward spiral of solipsistic interpretation. It is a hermeneutical circle that erupts into action' (Blosser, 2012:207). Becoming a valuable selfhood is not only the result of an act of imagination, but of an act of will (Ricoeur, 1992). Significantly, as the unified identity exists to be responsive to and act in ways that generate responses from others, the self in action is a social preserving rather than an autonomy preserving self. Becoming a valuable selfhood requires ethical

¹³ Radden and Fordyce (2006) question the ethical demands of such an approach on those tasked with holding, preserving and updating the narrative and suggest the notion of 'co-narrator' cannot be sustained in severe dementia.

engagement, reconnecting with the human need for recognition. This return to practical life in the public realm with the aim of living a good life is considered below.

The ideal of the narrative unity of life and the aim of a good life

Upon returning to the level of practical life, Ricoeur (1992) revisits and considerably extends his account of the narrative pre-figuration of action, as provisionally set out in *Time and Narrative*, to enable identity to be configured in meaningful ways. In so doing, he characterises action in terms of a nesting of constitutive levels of *praxis*, which can be presented in terms of relative levels of complexity (ibid). Reflecting that in many narratives the self seeks its identity on the scale of an entire life, Ricoeur (1992:153-157) proposes that narrative lends itself to an understanding of identity through the configuration of the 'practices' that direct individual, intimate, shared and public lives, and in terms of the 'life plans' one constructs, composed within the horizon or guiding ideal of a 'narrative unity of a life'. These concepts introduce important interpretive possibilities to the study and I consider each below.

Practices

Ricoeur (1992) explains that the concept of '*practice*' is more widely used in France than in English speaking countries, offering more commonplace examples of games, arts and professions to facilitate understanding. His thinking in this respect is similar to continental philosophers such as Bourdieu (1977). Using the example of moving a pawn on a chess board, Ricoeur (1992) establishes that practices are comprised of basic actions configured by 'constitutive rules' (pp154-155) that give a basic action its meaning. These are not moral rules, but internal rules that offer meaning within the practice. As the rules are agreed, constitutive rules signal the 'interactive character belonging to most practices'. A practice is 'based on actions in which an agent takes into account, as a matter of principle, the actions of others' (p155). Drawing upon the work of Weber (1978), he goes on to advance an understanding of action that:

'[I]ncludes all human behaviour when and in so far the acting individual attaches a subjective meaning to it. Action in this sense may be overt or purely inward or subjective; it may consist of positive intervention in a situation, or of deliberately refraining from such intervention or passively acquiescing in the situation' (Ricoeur, 1992:155).

This expanded definition of (inter)action has important consequences, establishing that 'omitting, enduring and suffering are as much data of interaction as data of subjective understanding. Not acting is still acting, neglecting, forgetting to do something is also letting things be done by someone else' (p157). As such, the theory is explicitly

extended from acting to suffering beings. In a further development of this argument, he highlights that, over time, interaction becomes an internal – internalised - relation:

‘[I]n the relation of learning as it shades, little by little, into an acquired competence; one can, therefore, play alone, garden alone, do research alone...These constitutive rules come from much further back than from any solitary performer; it is from someone else that the practice of a skill, profession, game or an art is learned’ (Ricoeur, 1992:156).

This temporal relation further enriches our understanding of identity, revealing aspects where selfhood has been eclipsed by sameness -habits, dispositions and identifications that have become part of the stable identity were once acquired through action in associations with others and the connectedness of human life.

Life plans

At the higher level of *praxis*, ‘life plans’ refer to a set of ideals related to the vast practical units that make up family life, working life, leisure, community and so on, and which concern the things we care about and aspire to (Ricoeur, 1992). However, far from being grounded in linear assumptions that suggest a presumed capacity to colonise the future, ‘life plans’ take a shape that is necessarily mobile and changeable. Moreover, in depicting life plans as sitting at a higher level of organisation, Ricoeur (1992:157) is keen to establish that the practical field is not constituted from the ground up, but is ‘formed through a back-and-forth movement between more and less distant ideals’. Nevertheless, the suggestion that existence is narratively configured in terms of ‘life’ plans opens onto the final level in the hierarchy, the ‘narrative unity of a life’. The literature on temporal orientations in later life, notably more generative imagined futures (e.g. McFadden and Atchley, 2001) is salient in this respect.

The guiding ideal of the ‘narrative unity of a life’

While ‘practices’ and ‘life plans’ are inherent in action, the concept of the ‘*narrative unity of a life*’ serves as a limiting ideal towards which the human agent aims (Hall, 2007). Ricoeur (1992:158-163) considers in some detail the differences between literary fiction and ‘real life’ narratives, and problematises the notion of ‘the narrative unity of a life’ proposed by MacIntyre (1985) on several counts, reasserting his understanding of narrative as rooted in life, but a poetic imitation.

First, Ricoeur (1992:160) highlights ‘the equivocalness of the notion of author in real life’, stressing that we may be the narrator of, or character in the life narrative, but we are co-authors at best. Ricoeur (1992:160) then turns to ‘the narrative incompleteness of a life’, whereby the constraints of being within time preclude the possibility that a

life can be grasped as a unity; birth and early memories, death and the final stages of life exist only in the narrating activities of others. To this he adds the observation that it is possible to weave several plots or recount several stories from the same events, detracting further from the notion of an ending in the absolute sense (p161). Next, he draws attention to the 'entanglement of life histories', such that huge parts of a life are part of the life history of others, and he contrasts this with the enclosed world of the fictional narrative. Finally, he questions the inclusion of seemingly entirely retrospective life histories within the 'dialectic between remembrance and anticipation' (ibid). It is problematic to draw a sharp opposition between living and telling as this lowers the stakes and 'loses sight of the complex existential significance of narrative' (Meretoga, 2014:90-91). It is equally problematic to equate narrative and experience with each other as this undermines critical reflection on how cultural and historical narratives shape our (self-) understanding and regulate our being in the world.

Ultimately, Ricoeur (1992:161) retains the notion of the 'narrative unity of a life' as an ideal, a mixture of fabulation and actual experience, yet practically useful. Indeed, it is precisely because of the elusive nature of real life that we need the help of plots, borrowed from history or fiction, to articulate narratively retrospection and prospection. He emphasises the connection the narrative makes between estimations applied to actions and the evaluations of persons themselves. While the notion of 'life plans' places an accent on the voluntary or even wilful side of existence, the notion of 'narrative unity' underscores the organisation of the mix of intention, causes, happenings and chance that we find in all stories (p178). Against the 'narrative unity of a life' lived so far, he posits the possibility or aim of the good life, which comprises 'the nebula of ideals and dreams of achievements with regard to which life is held to be more or less fulfilled. It is the plane of "time lost" and "time regained"' (p179).

Narrative configuration and the ethical aim of a good life

For Ricoeur (1992), the ethical aim of the good life is self-esteem¹⁴, where 'good' is an evaluation informed inter-subjectively. Self-esteem means being able to attest to oneself as being the worthy subject of a good life. It can fail and depends upon the words and actions of others. Between the aim of a 'good life' and everyday practices,

¹⁴ For Ricoeur (1992) self-esteem is tied to the teleological (ethical aim of a good life). Self-respect is tied to the deontological (duty-bound / obligatory evaluation of the moral worth or rightness of specific actions). The latter relates to equality in law, legal rights, constraints and moral norms. While tensions can arise between 'the two faces of just', the good and the right, both are important, can be integrated, and together provide an overall sense of the worth of a life.

Ricoeur (1992) identifies a sort of hermeneutical circle by virtue of the back and forth movement between the nested levels of *praxis*. It is this two-way movement between practices and their constitutive rules, more flexible 'life plans' and the guiding ideal of the 'narrative unity of a life' that creates conditions ripe for narrative configuration, through the desire to bring concordance from discordance. This can be likened to a text in which the whole and the part are to be understood each in terms of the other. Once again, Ricoeur (1992:162-163) emphasises that the plot is not fixed. As the agent continues to act and suffer, new events take place and new episodes are added, each folded back into the fabric of one's individual and shared narratives, harmoniously or discordantly. Old events may also be removed or assume new meanings, opening up or closing down possibilities for future action. For the human agent, interpreting the text of action is interpreting himself.

Applicability of narrative identity to the study

Ricoeur's (1992) conceptualisation of narrative identity appears, I suggest, to offer vast potential to the study, providing a theoretical mechanism for interpreting the ways in which disparate actions and events enacted and recounted within time, and the in-between happenings that occur over time are, or are not, incorporated into the unfolding narratives of older people living with dementia. It does so by facilitating an exploration of the relationship between everyday activity and identity via the mediation of narrative, and in ways that challenge the philosophical construction of personal identity as sameness, engaging directly and dialectically with diversity and change over time. Additionally, his dialogic account of selfhood and dialectic between self and an expanded account of the Other ensures that (narrative) identity is rich with intersubjective elements and provides for a nuanced understanding of forms of recognition and misrecognition.

The implications of Ricoeur's (1992) dialectic between identity as sameness and selfhood, and between self and Other, have been considered in the literature on people with advanced dementia, where the ability to speak of the person remaining themselves in as much as 'being another' was valued (e.g. Radden and Fordyce, 2006). Ricoeur's (1992) attention to the co-authored nature of all narratives and to shared memories, particularly through the phenomenon of growing older together (Ricoeur, 2004) lends support to mechanisms seeking to sustain the narrative agency and identity of people as the effects of dementia increase. Through his meditation on interpersonal solicitude, this notion is extended from informal turn taking by couples

(Beard et al, 2009) through purposeful co-construction of narratives by people with dementia and researchers (Keady and Williams, 2007), quilting narrative fragments (Moore and Davis, 2002) to actively holding the story of a loved one until death (Purcell, 2013; Randall, 2009). It also extends the narrative agency of people with dementia as they continue to shape the narratives and lives of others (Baldwin, 2008; Purcell, 2013). This allows not only the mere sameness of the person, but also aspects of selfhood to be retained for longer. It also affords the possibility for new experiences to be woven into the still unfolding and increasingly co-constructed and interconnected narratives of the person and those involved in the person's life.

Throughout this discussion, I have sought to ensure that the theoretical resources and underpinning concepts I deploy do not inadvertently discount people with advanced dementia from the category of person. For the purposes of the present study, engagement with the dialectic between stability and uncertainty at the level of a given acting situation may be extended to engagement with the identity configuration of older people with dementia who are striving to continue to go about their everyday activities, to demonstrate self-constancy and continue to be recognised by inter-personal and institutional Others. While this opens up positive opportunities, there is also the risk that narrative identities may be co-opted by known others, dominant narratives or cultural metaphors, or that deficient identities may be ascribed (Beard, 2016). Alongside this is the existential threat of illness producing narrative wrecks (Dworkin, 1993). In addition, extension may be facilitated from imagined possibilities for action within a given situation to the ideal of narrative unity and the possibility of a good life, underscoring that dementia is only one aspect of experience and it is important not to lose sight of the longer and broader narrative. In this respect, insights from the field of narrative gerontology can enhance the relevance and applicability of Ricoeur's theorising to an older population.

Narrative Identity Development and Insights from Narrative Gerontology

While the study is not concerned with 'life stories' per se, Ricoeur's (1992) perspective nevertheless appears salient in light of the emphasis within the ageing and dementia literature on sharing spontaneous memories, more purposeful social reminiscence and life review. The meanings of time, time's passing and time's tenses shift as we age (Achenbaum, 2001). Older people also have a lifetime of experience to draw upon, 'biographically accrued capital' (Mader, 1996:43). The notion of 'lifetime' underscores

the temporal nature of human existence in the sense that it is finite, and narrative is the means by which we try to make meaning and find unity in our lives as a whole (Ricoeur, 1992). This imperative may be stimulated by the anticipation of an ending, increasing the relative importance of emotion-related over knowledge-related goals (Carstensen, 1992; Carstensen et al, 1995; Erikson, 1980; Frankl, 1986; Randall, 2008) consistent with Bartlett's (2012) findings in her study involving dementia activists. It may also result in broader temporal horizons through generativity (Tornstram, 1996).

Revisiting life fragments, bounded episodes or previous life chapters can constitute highly valued everyday activities for older people, particularly when the laying down of new life episodes is no longer feasible or a priority. Reviewing previous life episodes can forestall narrative foreclosure (Bohlmeijer et al, 2011; Freeman, 2000) whereby no new meanings can be found in the future, present or past. This has important implications for both dimensions of identity and the dialectic between them. Overall, Ricoeur's perspective holds promise to facilitate the study aim of exploring how ordinary, everyday life is accomplished by older people living with dementia. By engaging directly with the constitutive function of narrative, it may also enrich current conceptualisations of narrative citizenship. Finally, anchored by a relational, dialogic self, it addresses Fisher's (2012) demands to preserve the complexities of identity and facilitate a nuanced understanding of forms of recognition and misrecognition, augmenting the application of citizenship-as-practice in dementia studies.

Reflections and Way Forward

This chapter first highlighted the potential of Ricoeur's (1984) concept of *mimesis* to situate the everyday activities of older people living with dementia within the physical, socio-cultural and temporal world. It facilitates exploration and interpretation of the various relationships at play within a given acting situation through its articulation of the semantics of action, symbolic resources of the practical field and temporal dimension of action. By depicting these resources as the 'pre-narrative quality of action', and introducing the ordering and creative functions of emplotment, Ricoeur (1984) makes explicit the relationship between narrative and practical life. This introduces interpretive and methodological possibilities, notably by facilitating differentiation of the various layers of meaning-making.

Ricoeur's (1992) conceptualisation of narrative identity also provides a comprehensive mechanism for exploring the relationships between practical and ethical life, narrative

and identity, both within time and over time. This perspective provides a robust theoretical basis for moving back and forth between the 'ordinary doing' of everyday activities within the exigencies of a particular acting situation, the ideal of the 'narrative unity of a life' and the aim of a good life, with and for others in just institutions. Importantly, he advances a notion of identity that permits diversity over time, preserves complexity, offers future possibilities and may facilitate nuanced understandings of forms of (mis)recognition. Given this potential, and mindful of the importance of framing research questions in ways that open up rather than close down possibilities for complex and radical self-representations through research participation (Fisher, 2012), I now set out the following research questions:

1. How do people (living with dementia) variously:
 - Construe 'everyday activity' and 'everyday life'?
 - Enact the activities that comprise everyday life?
 - Make meaning *in and through* these activities?
2. How do people (living with dementia) variously negotiate and make sense of the obstacles, dilemmas and possibilities of everyday life *through* time?
3. How is memory loss / dementia incorporated into the unfolding narratives and narrative identities of people living with dementia? What part does 'dementia' play, or not play, within these narrative configurations?
4. How might the narrative-in-action methodology enhance future understandings of the (narrative) citizenship of people living with dementia?
5. What are the theoretical and societal implications of the study from a social citizenship perspective?

Moving forward, the above discussion and resultant research questions suggest the need for engagement with everyday activities and the small stories of everyday life as they are enacted and recounted *within the flow of actions* and also with events and happenings *over time*. It also suggests the need for analytical attention to way in which events, happenings and associated meanings are incorporated into unfolding narratives and complex, dynamic identities. These requirements are addressed in Chapter Five.

Chapter Five

Carving a Path to the Domain of the Possible

Overview

This Narrative Inquiry study is grounded in the narrative theories described in the previous chapter. Ricoeur's (1992) narrative theorising understands selfhood as lived in the mode of possibility and the research questions seek to open up rather than close down possibilities for complex self-representations through research participation. In this chapter, I seek to further develop my aspiration to enter 'the domain of the possible' (Taylor, 2008:324) by creating an appropriate methodological pathway.

The study is located within the 'fourth moment' (Bartlett and O'Connor, 2010) in dementia studies and employs a social citizenship value lens. This lens not only requires appropriate theoretical underpinnings and research questions, but also demands new ways of conducting research with and for older people living with dementia. At a minimum, research studies must recognise the diversity of older people with dementia, remain attentive to possible power imbalances within relationships, facilitate meaningful participation and engage deeply with ethical research practice issues (ibid). In this chapter, I describe how these imperatives were built into the study design. I reflect upon the success of their application in Chapter Nine.

Narrative Inquiry seeks to understand life as lived and as expressed in practice by embodied persons (Clandinin and Connelly, 2000). In Chapter Four, I identified the need to engage with the everyday activities and the small stories of everyday life as they are enacted and recounted *within time*, and also with events and happenings *over a period of time* in order to address the research questions. Ethnographic methodology takes seriously the fact that experience takes place in real time and uses participation in everyday life as its main source of acquiring knowledge.

In the sections that follow I summarise the features of ethnography that are, and are not, of relevance to this study, before outlining the study design and the various stages of recruitment. I then summarise my experiences of creating data with the participants, which are elaborated upon in Chapter Six. I detail the process of narrative analysis, drawing upon Ricoeur's concepts of *mimesis*, emplotment and narrative identity. I also reflect upon the criteria for determining the trustworthiness and authenticity of the

narrative configurations and the accompanying interpretations presented in Chapters Seven and Eight, underscoring the role of reflexivity throughout.

Locating Ethnographic Methods within the Narrative Inquiry

As described above, a social citizenship value lens requires research studies to remain attentive to power imbalances within research relationships and facilitate meaningful participation (Bartlett and O'Connor, 2010). Participatory research is concerned with 'how' research is carried out rather than which data creation methods are used. Nevertheless, thinking carefully about data creation can help to promote a sense of citizenship (p104). At the outset, I was determined to ensure sufficient elasticity in my approach to respect the varied lifestyles, circumstances and distinctive attitudes to and ways of ageing for each participant. I was keen to be able to respond to participants' understandings of and varying abilities to engage in everyday 'activities', avoiding ageist assumptions. I also recognised the need to work with different degrees of willingness to involve me in activities, should they take place in different social contexts. In short, I wanted to start where people are at (Beard, 2016) and I recognised the necessity of designing flexibility 'in' from the outset.

Ethnographic research is an emergent endeavour wherein the 'planning process is begun but not completed before the researcher enters the field' (Whyte, 1984:35). Although a skeletal framework for the study is likely to exist prior to beginning research, the study only fully takes form upon entering the field. The emergent nature of ethnographic research therefore held the capacity to facilitate the complexity, heterogeneity, and uncertainty of older people's everyday experiences without restricting the range of phenomena that might be explored through the study. Ethnography is fundamentally about culture (Van Maanen, 1998). Culture in turn can be defined as the 'production and consumption of everyday life as well as how everyday life is accounted for and storied into meaningful orders of persons and things' (Goodall, 2000:86). This sat comfortably with the original study aim and Alsaker and Josephsson (2010) highlight that studying a person engaged in everyday activities will make visible his or her connections to culture and its claims of ordinariness.

Traditionally ethnography requires that the researcher immerses herself in a social situation and the lives of participants to generate real world observations about actions and events in a pragmatic, reflexive and emergent way, (Greenhalgh and Swinglehurst, 2011; Prus, 1996). While ethnography has been used successfully in the 'local cultures'

of care homes for forty years (e.g. Gubrium, 1975; Cook, 2003; Watson, 2015), I considered 'immersion' in people's daily lives in their own homes and local communities too intrusive. The notion of mini-ethnography allows for an approach that shares the same ethos, but does not study a whole culture (Hastrup, 2003 in Alsaker et al, 2009).

The narrative-in-action methodology developed by Alsaker et al (2009) is an example of a mini-ethnography that directly accesses ongoing action in an everyday context. Ricoeur's (1984) understanding of action illustrates the process quality of everyday activity and the concrete connection to meaning. (Clandinin, 2007) suggests that it is the concreteness of activities that makes human action accessible to research. The immediate situation, nested in a particular culture, allows for participation, coaction, observation, description, and interpretation (ibid). The possibilities for participation, coaction and observation turn attention to data creation methods, as considered below.

Thinking about Possible Data Creation Methods

Narrative-in-action was developed by Alsaker et al (2009) to facilitate research with women with chronic rheumatoid conditions. Studying daily life among older persons with dementia requires particularly careful methodological consideration (Clarke and Keady, 2002) and the translation of the narrative-in-action methodology raises a number of issues. While the methodology has been used in a study of older people with depression (Nyman et al, 2012), it has not, to my knowledge, been used with older people with dementia. I therefore turned to empirical research in the field of dementia to ascertain if I could find support for or barriers to its application.

The subjective experiences of people with mild and moderate dementia have been accessed in research for many years (Wilkinson 2002, Hellstrom et al 2007) and, with the advent of earlier diagnosis, many people living with dementia can and do provide coherent accounts of their experiences (Beard, 2016). Nevertheless, as the condition progresses, persons increasingly have problems constructing a verbal narrative that connects various events together into a coherent story (Herman, 2009). Hulko (2004; 2009) has highlighted the dominance of more articulate and multiply privileged voices within dementia research and reflecting the heterogeneity of people with dementia within this Narrative Inquiry was a key consideration. As I was interested in experience as expressed in practice, the potential of engaging with observations, actions, meanings

and stories of the moment, together with less effortful recollections and spontaneous memories, as suggested by Ricoeur's (1984) mimetic theory, was attractive.

I drew encouragement from studies employing similar data creation methods, but without the application of mimetic theory. Specifically, 'in-situ conversations' have proved particularly beneficial in supporting people with dementia to participate in research (Bamford and Bruce, 2000). This approach dispenses with the need for recall and can help to foreground multi-sensory experiences. More recently, there has been an increasing interest in the use of 'walking and talking' methods across the social sciences (Emmel and Clark, 2009) and it has been suggested that they could fruitfully be used with people with dementia (Bartlett and O'Connor, 2010) subject to physical abilities. These methods shift the emphasis from telling to showing or enacting, reducing verbal communication demands, although placing events and experiences in their spatial context can help participants to articulate their thoughts and add detail to the researcher's understanding (Emmel and Clark, 2009). They also provide opportunities for the serendipitous and the unanticipated.

The above methods afford participants a greater degree of control over the research process, fitting in with their daily lives. It appeared that offering a choice or combination of these methods would offer greater scope to respect the capacities and preferences of the participants. Employing different data creation methods not only helps to ameliorate problems that may arise with people who have diminished cognitive or communicative abilities (Rowles and Reinharz, 1988), but also affords participants different means and opportunities to express themselves (Ikels, Keith and Fry, 1988). Drawing upon mimetic theory to access meaning-making-in-action held the potential to enhance these methods by increasing the transparency of analyses.

Piloting the methods

The suitability of the proposed methods was lightly tested through an informal pilot with older family members, former neighbours and the parents of friends, progressing from people well known to me to persons largely unknown, including two people with dementia. Alsaker et al (2009) advise that the enacted narrative facilitator must make a deliberate choice to position herself as 'actively passive' and refrain from bringing in topics from outside the actual ongoing activity, consistent with the theoretical intent. Piloting proved important in understanding the practicalities of doing so (it did not come naturally) and in balancing this 'active passivity' with both strengths-based

engagement and more traditional participation observation approaches. It also became apparent that different types of activities, from the routine or mundane to the more socially or culturally significant, presented different possibilities for contextualising experiences and required different levels of participation on my part. The pilot also underscored the benefits of sustained involvement over time. The implications of this were incorporated into the study design, and I sought to spend time with participants as they enacted a blend of mundane and slightly more significant activities, proposing to meet with each participant up to seven times over a period of approximately six months.



Figure 5.1 - Data Generation Methods

Thinking about Recruitment

When it came to thinking about participant recruitment, I sought to recognise the heterogeneity of older people living with dementia. Although aware that my task would be more a case of trying to find a small but diverse group of people who might be willing to take part, rather than to 'draw a sample', I did have to come up with a 'sampling frame' from which people with 'certain characteristics' could be 'selected' and then invited to take part. For logistical reasons, I also had to plan for a certain number of participants, with the understanding that the actual number might be lower, or indeed higher, than this figure. I noted that other Narrative Inquiry studies generally featured between three and eight people, depending on their purpose. My interest in diversity pulled me towards the higher end of this range, my interest in developing nuanced understandings towards the lower end. I kept an open mind.

Inclusion and exclusion criteria

Following close reading of the Adults with Incapacity Act (Scotland) 2001, particularly Part 5 Section 51, I concluded that the study aims could be achieved without the inclusion of persons unable to consent and therefore I should not seek to include them. The data creation methods and overall study aim also did not lend themselves to a fully

inclusive approach. From the outset, my interest has been the experiences of older people with dementia living at home and the 'parent population of interest' for this study was provisionally defined as 'older people (aged 65 years and over) with a diagnosis of a dementia sub-type who live at home and are able to give consent'.

Literature review indicated that participation in research studies by people with dementia has largely (although not purposefully) been confined to the more articulate and privileged voices (Hulko, 2009). I therefore hoped to facilitate the participation of older people with dementia with diverse 'social locations', with a particular interest in including socially and economically disadvantaged persons. With these parameters in mind, my attention turned to thinking about how best to gain access to people to invite them to take part. This proved challenging.

Turning again to previous studies, I determined that the most fruitful recruitment sites tended to be memory clinics, "D (dementia) cafes" and Alzheimer Society community initiatives. As the research study is concerned with people's experiences as stakeholders in everyday life, I did briefly consider the latter options as I initially felt that a social setting was preferable to access through a clinical facility. However, I was interested in exploring everyday life *away* from dementia, in the realm of the ordinary. As described in Chapter Three, a dementia diagnosis does not necessarily take centre stage in older people's lives and I was keen to try to include people who do and do not identify with the diagnosis. The materials later prepared for potential participants referred to 'people with memory problems or dementia' to facilitate this aspiration.

As the limitations of restricting the search to locations or social groups with a dementia-specific orientation became apparent, I identified GP records as the optimum 'sample frame'. I thought that I would need to recruit people from across multiple sites because of the participatory demands of the study design. General Practices are classified according to the deprivation category of their patient population and I determined that they represented a potentially useful initial means of accessing older people with a diagnosis of a dementia sub-type with varying socio-economic statuses. The 'population of interest' was therefore further restricted to 'older people with dementia living at home who are able to consent and are registered with a GP practice'.

The use of GP records allows exclusion criteria to be applied before approaching potential participants, such as where the person has recently been diagnosed with

dementia or has another terminal illness. People who have recently taken part in studies and those who have asked not to be contacted can be automatically excluded. I recognised the benefits of avoiding an insensitive or unwanted approach and identified the importance of giving GPs discretion to use their personal knowledge to exclude people on grounds over and above those discernible from categories in the GP records, including recent significant life changes, such as a family bereavement, or potential future changes, such as moving to a care home.

Provisionally identifying Participant Identification Centres

GPs have a duty of care to their patients and need to balance risk with empowering people to take part in research. I appreciated that it would be important for GPs to receive a clear and transparent explanation of the research objectives, notably the commitment required of participants (McKillop and Wilkinson, 2004; Dewing, 2007). I therefore prepared an Information Sheet for Participant Identification Centres (Appendix II). This included process details to ensure there would be no breach of confidentiality and to facilitate agreement and mutual adherence to the highest standards of research practice and best practice guidelines (Wellcome Trust, 2009).

At this point, my background working in health and social care service improvement proved useful and I was able to draw upon the assistance of former colleagues. One Primary Care lead sent out a favourable letter of introduction to his colleagues in three General Practices with populations with diverse deprivation statuses (percentage of practice patients living in data zones marked as the 15% most deprived in Scotland). The GPs indicated that they would be willing to act as a Participation Identification Centre (PIC) in principle, subject of course to my securing a favourable ethical opinion. All three practices were located within a single health board area (NHS Lothian), achieving logistical benefits in terms of their familiarity and proximity to me. The final inclusion and exclusion criteria for the study are set out in table 5.1 overleaf. The decision to recruit through GP records introduced some specific ethical stipulations, as described below.

Inclusion Criteria	Exclusion Criteria
Men and women who: <ul style="list-style-type: none"> - have a diagnosis of a dementia sub-type - live at home - are able to provide informed consent - are aged 65 years or over - are registered with (one of three pre-defined) GP practices in NHS Lothian 	People: <ul style="list-style-type: none"> - diagnosed with 'dementia' within the previous 3 months (to allow time for adjustment) - with a terminal illness who are expected to live for less than one year - who have experienced recent significant life changes

Table 5.1- Inclusion and Exclusion Criteria

Seeking a Favourable Ethical Opinion

My decision to recruit through GP surgeries in NHS Lothian meant that ethical approval was legally required through the NHS Scotland South Scotland Research Ethics Committee before I could begin the fieldwork. I found completing the ethics application helpful, forcing me to think through issues that simply did not arise when working in a service improvement context. I believe that I have always practiced in an ethical way and have favoured participatory and inclusive methods that participants have invariably found enjoyable and often beneficial and even empowering. It was instructive to consider scenarios from the perspective of possible harms.

As discussed above, in designing the study I sought to ensure maximum flexibility for participation and to remain open, alert and responsive to emergent opportunities. However, this openness does not sit comfortably with traditional notions of research planning, where authorising bodies, understandably, want to know in advance exactly what you will be doing with potentially 'vulnerable' adults. Three of the guiding principles of the NHS REC are that research participation should be voluntary, that informed consent should be obtained prior to beginning the research, and that no harm should be done. It has been argued that the bureaucratic anticipatory nature of NHS RECs makes ethnographic research almost impossible (Murphy and Dingwall, 2007). The difficulties are attributed not only to the emergent design of studies, but also to the extended period of time that researchers spend developing trusting relationships and negotiating participation, where consent is understood as a relational process rather than a contractual agreement. The public and semi-public nature of the settings typically studied in ethnographic research may also be deemed risky (Murphy and

Dingwall, 2007). Given these concerns, my experience of obtaining a favourable opinion from the Research Ethics Committee (REC) proved less problematic than anticipated.

During the meeting with the REC, the one question that I was grilled on concerned the sensitive management of ending research relationships, given my intention to meet with participants over several months. In a way, I was pleasantly surprised that the potential for emotional harm was a priority and I drew some reassurance from my ability to address the Committee's concerns. The study received ethical approval from the University of Edinburgh, School of Health in Social Science (ISSH004 – Appendix III) and met with a favourable ethical opinion from the South of Scotland Research Ethics Committee (15/SS/0076 - Appendix IV). I also submitted a substantial amendment shortly after entering the field to counter an initial oversight. Specifically, I had not made provision to enable the spouse of the person with dementia to participate fully in the study, where this was consistent with the couple's preferences and the nature of their relationship. This important corrective also met with a favourable opinion (15/SS/0076-AM01-S1-1 - Appendix VI).

The REC review is a form of preventative ethics, which serves to anticipate and divert potential problems and is only a first step. A social citizenship lens also demands a more far-reaching assessment of the ethical issues underpinning research in the area of dementia (Bartlett and O'Connor, 2010) and I reflect upon the ethical dilemmas encountered in the 'small moments of doing' the research (Stern, 2004), the management of endings and the type of participation afforded in Chapter Nine.

Encountering Delays: Losing Hope

As I was seeking to recruit through General Practices, I also had to obtain a Clinical Research Access Letter and NHS Research Passport. This required undergoing relevant disclosure, occupational health checks and vaccinations. It was a long and drawn out process, which proved frustrating and resulted in the loss of several months of study time. The core issue was a difference of opinion as to the type of disclosure statement that I required. Disclosure Scotland maintained that the research required basic disclosure, whereas the NHS felt standard disclosure was appropriate as I would be working alone with older people with dementia. I agreed. For a while it seemed that a stalemate had been reached, which I was powerless to influence. I would make a revised submission to Disclosure Scotland only to have my application form returned, rejected, several weeks later. I became very disheartened over this period. The

situation was eventually resolved when NHS Lothian took the pragmatic decision to accept the basic disclosure and supporting chain of email correspondence. I secured the necessary Clinical Research Access Letter and NHS Research Passport from NHS Lothian Research and Development (2015/0265 -Appendix V).

Prior to this, I had stepped back from the research study for a few months to help out with teaching and research in the University, which was necessary due to the coincidental long-term sickness of two staff members, in effect front-loading the contributions to the School that were expected under the terms of my Career Development Scholarship. The combined delay had further ramifications – by the time I obtained my NHS Passport, two of the three GPs who has provisionally agreed to support me had taken early retirement. At this point I began to feel that the study was doomed. My hopes rested on the one remaining GP.

Moving to Recruitment: Silver Linings

When I anxiously explained my predicament to the remaining GP, he could not have been more helpful. He took the time to have a long telephone conversation with me out of hours to better understand the study aims. The GP asked if it would compromise the study design if the mix of participants that I hoped for were all recruited through his practice. Thinking about this, I recognised that this could actually strengthen the study by situating the research in one small town. The GP also fully understood and endorsed the issues I was grappling with, as set out in Chapter Two. Although I had stipulated persons over the age of 65 years on the research materials, he recognised that I was interested in the experiences of his ‘core demographic’ when it came to dementia, namely people closer to 80 years of age. He also embraced my desire not to restrict study participation to more affluent, educated persons, and to recruit men and women with different living situations, educational or employment histories, and who may have other long-term conditions. He identified with my aspiration to recruit people who had responded in different ways to their diagnosis and indeed people with different attitudes and approaches to ageing generally. He was confident that recruitment would not be problematic. Hope was restored.

Identification of potential participants

The GP undertook to mail information about the study (Participation Information Leaflet (PIL) – Appendix VII and Invitation Letter - Appendix VIII) to people meeting the study inclusion criteria. In order to maintain patient trust, it is best practice for the

invitation to come from the GP on practice headed paper (Wellcome Trust, 2009) and the GP elected to personalise the invitation. I sent him an electronic copy of the letter and then posted a batch of stamped blank envelopes and copies of the Participant Information Leaflet to him. I printed the leaflet onto yellow card and it became known as 'the little yellow leaflet'.

The 'little yellow leaflet' and letter both invited potential participants to contact me directly if interested, either by email or by phone. This approach avoided disclosure of potential participants' details to me and offset the need to involve the GP in the actual recruitment to the study. In addition, potential participants must be contacted in a way that avoids possible worry or embarrassment, and the Letter of Invitation and Participant Information Sheet both stress that the person is free to choose whether or not to participate in the study, and that the decision will not affect the quality of their care or their relationship with the GP. It also offers the opportunity to discuss the study with me before making a decision as part of the informed consent process, described later in this chapter.

Response to the invitation to participate

A batch of ten letters was initially posted out, eliciting a favourable response from four people, three men and one woman, all of whom lived with their spouse. (Three other people made contact to offer reasons for not taking part and wishing me well). A second more targeted batch of letters was sent out in a bid to recruit another woman and someone living alone to the study and this resulted in one further person making contact. Initially I sought to recruit people with a diagnosis of a dementia sub-type to the study. However, it soon became apparent that some participants wished to take part with their spouses, consistent with their continuing sense of 'couplehood'. A substantial ethical amendment was raised to accommodate their preferences. This resulted in eight people being recruited to the study (three couples, one man and one woman) aged between 78 and 85 years. While the participants had the mix of 'social locations' and 'characteristics' that I hoped for, as Clandinin and Connelly (2000:141) rightly assert '[w]hen participants are known intimately as people, not merely as categorical representatives, categories fragment'. In Chapter Six, I introduce the participants, allowing the uniqueness, particularity and complexity of their lives and their identities to emerge over the subsequent chapters.

Consent Procedures

The study draws upon the concept of process consent (Dewing, 2007), which supplements the more conventional formal consenting process. This approach addresses concerns that cognitive and individualistic assumptions may deny people with dementia opportunities to participate in decision making. Instead, consent is revisited and renegotiated on an ongoing basis and is dependent upon the experience of involvement rather than participant recollection. Bartlett and Martin (2002:51) suggest that the continuous nature of qualitative research, which stresses the negotiated and relational processes between researcher and respondent, lends itself to a continual process of consent. 'Process consent' is particularly appropriate in research where there is reflexivity between data to be collected and data already collected, and where participants may wish to place limits on the information that is available as research data.

Careful consideration was given to the consent process throughout the study. Information about the study was presented in a format that each person was able to engage with. At least 48 hours lapses were allowed between providing information about the study and the commencement of data creation. Formal consent from the person with dementia was obtained during the initial visit, using the Participant Consent Form (Appendix IX). Following the acceptance of the substantial ethical amendment, an explanatory letter was given to the three couples who sought to participate jointly (Appendix X) and consent was obtained from the three spouses using the Consent Form for the Spouse of an Existing Participant (Appendix XI).

Each participant was asked for permission to notify the GP practice of the decision so that this could be recorded in their medical records and all agreed. While participants unable to give consent at the outset were excluded from the study, provision was made to allow for the possibility that participants might lose capacity to consent during the study. Specifically, the Participant Consent Form (Appendix IX) included a statement to the effect that should the person lose mental capacity during the study, they agree to any anonymised data collected prior to the loss of capacity to be used in data analysis. In practice, all participants were able to provide written consent and no one lost capacity during the study period. Had I had any doubt about the participant's continued capacity to consent, I would have spoken to a family member or approached the GP, depending on the individual situation.

Maintaining Confidentiality

Confidentiality is of paramount importance and every attempt was made to ensure this was respected. All data created were securely stored in locked drawers or on password-protected computers. My laptop was kept in a locked cabinet when not in use and was regularly backed up to the University server. I paid particular attention to the storage, handling and use of personal data, which I stored only on the University computer. With the notable exception of my named contact, I was the only person who had access to personal addresses. I conducted all transcription and deleted audio files from the server immediately afterwards.

Anonymity was negotiated with participants and all selected their own pseudonym, which proved a source of great amusement in some cases. Transcripts were anonymised in that all personal details and names of significant others were codified, together with data that risked identity disclosure. When using thick descriptions, anonymity cannot be guaranteed, and this possibility was discussed with and accepted by the participants.

Minimising Harm

While the study primarily concerns what people achieve as they go about their everyday activities, and how people live a good life (with dementia), I was also interested in understanding what gets in the way of such efforts. There was therefore the risk of confronting participants with potentially painful issues such as frailty, loss or stigma. I have prior experience of working with older people with dementia using participatory and creative methods in service improvement and applied research contexts, adopting an appreciative, strengths-based approach. I undertook to remain alert to any signs of distress and to ensure that participants knew where they could seek further local support, should they wish to speak in confidence to an external person in relation to any issues arising. Contact details were included on the Participant Information Leaflet.

Alongside this, there was also the possibility that participants might disclose details to me or that I might become aware of potentially harmful situations that required action. Participants were informed of the limits of confidentiality through the inclusion of appropriate statements in the Participant Information Leaflet and we discussed this during the initial meeting. No such issues arose in practice.

Researchers too must consider the emotional risks that they face. I was mindful of the emotional effects of the research, discussed any concerns during regular supervision and also contacted a former researcher / counsellor to talk through the ending of one particular relationship, which I reflect upon in Chapter Nine. A further risk relates to the issue of lone working, as much of the research entailed meeting with people in their own homes, and potentially confronting unpredictable situations. This was managed in accordance with University protocols, notably ensuring that an agreed named person knew where and when each visit was taking place and when it was expected to finish.

Data Creation: Doing Everyday Activities Together

My aspiration was as far as possible to put dementia on the back burner when I entered the field. I tried to engage with each participant in the context of his or her whole life rather than through the filter of the diagnostic label, enabling the participant to determine the part 'dementia' played in our discussions and shared activities.

The initial meeting

Once someone contacted me to express an interest in participating in the study, I made an appointment to visit the person in his or her home, together with a spouse, family member, or friend, where preferred by the person. The option of meeting at a preferred location was offered, but not taken up. The purpose of the visit was to sense check the person's understanding of the study and the full implications of involvement and to allow plenty of time for any questions to be asked. This introductory visit was critical in establishing rapport and as described in Chapter Six, very much set the tone for the rest of the study and the types of relationships developed. It served as an opportunity for the person and family member to get to know me and also enabled me to learn more about the person's daily routines and interests (McKillop and Wilkinson, 2004) and how 'everyday activity' was understood.

The formal aspect of the informed consent procedure was followed. Once written consent was given, the person was recruited onto the study and arrangements for the first data creation session made. Participants' were asked at the outset of the meeting if, should they decide to take part, they would be happy for me to write up notes about this introductory meeting. All were happy for this to take place, with some indicating they would be disappointed if I didn't. These introductory meetings without exception proved rich sources of data, with my notes providing the foundational content for Chapter Six.

Two participants with busier diaries gave early consideration to dates for the subsequent data creation sessions, with other participants preferring not to plan too far ahead and 'play it by ear'. I planned to allow a period of least 48 hours between providing information about the study and the commencement of any data collection, and in practice at least seven days elapsed between the initial contact and the introductory meeting.

Co-participating in everyday activities

During each of the subsequent meetings, I followed the natural stream of activity that the participant would engage in ordinarily and as chosen and initiated by them, consistent with the narrative-in-action methodology. The complete list of activities is documented for each participant in Chapter Six, but included chatting over a cup of tea, gardening, shopping, pottering around, taking part in an aquarobics class, 'raking round' charity shops, meeting 'the boys' at the local golf club and visiting sites of historical interest. Each of these sessions was expected to last between thirty minutes and two to three hours, as negotiated with the participant, with the actual duration adjusted in response to the way the participant felt on the day. Most sessions lasted around three hours, in line with participant preferences.

What's 'special'?

My original intention was to intersperse three data creation sessions co-participating in more mundane activities with two sessions doing activities that held slightly more personal, social or cultural significance for the participant. In practice, the mix of activities did happen, although not necessarily in accordance with the rather formal sounding pattern that I had proposed. In one case, all meetings took place within the couple's home, with events such as family popping in or looking through rediscovered letters transforming these data sessions into occasions with greater significance for them. Participants inevitably had different understandings of 'special.'

Accounting for my presence

During these data creation sessions, I interacted with others present or encountered along the way, engaging in conversations, participating in activities, helping out or trying not to get too much in the way as appropriate. Where encounters with others were pre-planned, how best to account for my presence was negotiated in advance with the participant and relevant others. For instance, 'the boys at the golf club' were told that I was a researcher before I joined them, although the nature of the research

was modified to 'wellbeing in later life,' as the participant did not identify with his Alzheimer's diagnosis. There were inevitably some incidental encounters with neighbours or known others that required the more spontaneous management of introductions. In most instances, I had previously established how the participant wished to account for my presence, with two participants in particular not wanting people to think I was their 'minder' or 'social worker' and it fell to the participant to use their preferred descriptor. One participant did deviate from the 'script', introducing me in various ways including 'a younger model I've traded the wife in for' or 'she's helping me out with a wee photography project, wink, wink'. This was entirely consistent with his tactical use of humour to avoid answering questions and was readily accepted.

In for the long haul

By meeting with participants on different occasions over time, I was able to be part of the ongoing process of engaging in everyday activities. This gave me access to stories that extended from past experiences to prospective future events and happenings, through times of loss of friends, and their struggles to create meaning around different everyday situations. Sustained engagement facilitated the chance to discover whether possibilities considered were actualised, sustained, constrained, discounted or denied. Over the course of the study, I also spoke with participants by phone in between meetings and my relationship with each participant developed in different ways, as discussed in Chapter Six.

The wrap-up meeting

A final meeting was arranged, intended to take the form of a review and thankyou session. This was an opportunity to sense check emerging 'findings' in the form of loose possible plotlines. In one case, the final meeting did not happen as the participant's wife was taken seriously ill and he was simply too distraught to think about the research study. I sent him a card. Otherwise, it was important to close the research relationship in a validating manner and I gave the participant a handwritten thankyou card and small token of appreciation.

Writing and Reflexivity

Field notes

A key focus of this research study is action – what people do as well as the conversations that take place in the course of the 'ordinary doing' of everyday life. Field notes about what transpired are therefore critical. Collecting this kind of research

material requires that notes from the encounters must be written afterwards, together with reflections and emergent analytic propositions. Collecting data by means of video recording could give a more accurate access to real-time action, but it is difficult to capture situational moves, especially where driving or walking are part of the participant observation. After each encounter, field notes were immediately recorded digitally. I built in time after each meeting to do so and I would drive to a quiet spot, put my seat back and then try to replay the scenes in my head, frame by frame, narrating my recollection into the recorder. The average length of time it took me to complete this exercise was just over one hour. This follows the approach outlined by Holloway and Wheeler (2010).

Although the methodology developed by Alsaker et al (2009) does not stipulate the use of an audio recorder to capture conversations, I found this useful and audio recorded my face-to-face meetings with the participants wherever it was practical and unobtrusive to do so. For instance, I clearly could not use the recorder when I took part in an aquarobics class with one participant and it would have been inappropriate to do so while walking through a supermarket. When I was outside, the noise of traffic or the wind made transcription difficult and I tended to use these recordings more as an aide memoire to make sure that my own recollections were complete. On other occasions, such as when chatting to participants in their homes, using the recorder did not feel uncomfortable and I recorded the entire session. I then transcribed the recording, annotating my own thoughts in italics.

The typed record for each meeting was between 12 to 17 pages in length. Phone call records varied from less than half a page to six pages. The research material consisted of approximately 750 pages of written text from a total of 45 face to face meetings and 58 telephone conversations. Sanjek (1990) suggests that the writing of field notes is indistinguishable from analysis as the process of writing contributes to the process of making sense. Thus, writing is a research tool in its own right (Speedy, 2005). My own experience aligns closely with these suggestions and I often began to make connections between events and happenings as I typed. Example field notes are provided at Appendix XII.

Reflexivity and keeping a journal

As alluded to in the opening chapter of this thesis, Narrative Inquiry features to varying degrees the interplay between the researcher's own subjectivity and the subjectivities

of those whose lives and worlds are in view (Gubrium and Holstein, 2009). Reflexivity in qualitative research in general is a 'continuous endeavour' (Gough 2003), whereby the researcher turns a critical gaze on herself at all stages of the research process, to examine and make transparent how she, and intersubjective elements, influence and transform the research process and its outcomes (Etherington, 2007) in both subtle and more explicit ways (Doucet, 2008). It is particularly critical in Narrative Inquiry, where the data are not simple descriptions of sense-impressions, but dialogical productions resulting from interactions between participants and the researcher (Tierney, 1993).

The reflexive process is intended to ensure that research can be understood not only in terms of 'what' has come to be known but also 'how' it has come to be known, (Etherington, 2007) making visible and demystifying the construction of knowledge. Given the importance of reflexivity, throughout the study I maintained a reflexive log to keep a record of my evolving thoughts and feelings. This included both periods of writing at my desk to purposefully try to get my thoughts in order and more spontaneous reflections. I carried a notebook with me wherever I went in case I had any sudden thoughts, such as while on a bus. Much of the content took the form of reflections on what happened during my encounters in the field, how I felt after or before meeting with a participant and how I felt I should act on those thoughts and feelings.

Other entries were written as I tried to make sense of the academic texts that I was reading. For instance, as I tried to make sense of Ricoeur's (1984) description of the dynamic circular relationship between narrative and life, I was taken back in time to a school Chemistry class and ending up doodling the structure of Benzene. I remembered my teacher telling me the story of Kekule's daydream about a snake swallowing its own tail as he sat on a London omnibus. After years of struggle, he finally made the breakthrough from thinking about alternating double bonds to a dynamic circular ring of electrons, 'dancing mockingly before his eyes'. When I looked at my doodles (Appendix XIII) I realised I too had been thinking too rigidly; I had been thinking about the hermeneutic process as phased rather than continuous.

Events and happenings in ordinary life also proved instructive and several experiences had a significant influence on my thinking. These included attending a play at the Edinburgh Festival called '*Spilliken: A Love Story*', which was about a woman with

dementia and a robot built by her husband to look after her when he died. Despite this unlikely premise, it was the most heartbreakingly beautiful production I've ever seen. I cried big, fat, snow-like tears which fell slowly from start to finish. It made me think about shared memory in a completely different way and influenced my decision to favour narrative over thematic analysis.

Another important moment took place during a book reading by my favourite contemporary author, Maggie O'Farrell. When asked why she favoured non-chronological narration, she responded that she thought chronology was 'a bit over-rated', she didn't think about experience linearly, it's 'more like geography'. I found that analogy a useful concept to hold on to when thinking about the Narrative Inquiry landscape. I likened my forays onto it to 'going for a walk in the country', the path chosen through hills and valleys explaining why some things were in or out of plain sight, past events either sedimented in the layers of soil underfoot or still visible through traces, like a tiny glove caught upon a fence.

Reading Elvis Costello's (2015) autobiography entitled *Unfaithful Music and Disappearing Ink* triggered another significant shift in my thinking. The book details the end of his father's life after he developed dementia with Lewy bodies, including poignant accounts of the final days. I purposefully engaged with this as a break from Ricoeur's theorising, which I was making pretty heavy weather of. 'Elvis' hadn't spent much time with his father and their shared memories were few, yet something more important lay between them that 'couldn't be measured in time'. It was an important piece in the jigsaw, helping me to understand the limits of memory and that human connectedness does not depend upon it. In many respects, these experiences were as critical in shaping my thinking as my engagement with the academic literature and field notes. I include a selection in Appendix XIII.

Narrative Analysis

The next step was a big one. It entailed moving from field text and reflexive notes to research text, making sense of the different data sources through narrative analysis. The analysis drew upon the theoretical concepts of *mimesis*, emplotment and narrative identity. I also utilised the different levels of meaning-making set out in Ricoeur's (1984) conceptualisation of triple *mimesis* to differentiate my own interpretative activity (emplotment) from the meaning-making activities of the participants accessed within the flow of actions. The configured narratives are based on the empirical data,

my reflections and theoretical resources, and are also shaped by the things I learned from the literature reviews summarised in Chapters Two and Three, my preunderstandings and experiences.

Clandinin and Connelly (2000) highlight that whereas paradigmatic knowledge is focused on what is common among actions, narrative knowledge focuses on the particular and special characteristics of each action. Narrative reasoning operates by noticing the differences and diversity of people's behaviour. It attends to the temporal context and complex interaction of the elements that make each situation remarkable. The search is for data that will reveal uniqueness of the individual case and provide an understanding of its idiosyncrasy and particular complexity. Rather than reading across participant accounts to identify common elements and themes, in Narrative Inquiry the analysis moves from elements to stories.

The analytical process not only revealed the understandings that underlie the storied outcomes and associated interpretations presented in Chapter Eight, but also prompted me to reflect on the interpersonal processes that were crucial to developing and fully contextualising those understandings. Working through the field notes, I gained a deeper understanding of how each participant's understanding of and possibilities for enacting everyday activities shaped the possibilities for data creation, from the solitary to those conducted as a larger group. I also became aware of the way in which my relationship with each participant developed over the study, how this was related in part to the types of activities engaged in, and how each relationship fostered the various understandings. As relationships deepened, rather than posing a threat to 'rigor', this methodological sensitivity seemed to facilitate genuine understandings of the participants' experiences (Lofland, Snow, Anderson, and Lofland, 2006). It struck me as important to incorporate this learning in the research text.

Polkinghorne (1995) remarks that to understand the person, we must try to grasp the person's meanings and understandings. Experience is always in excess of language and felt meanings about a situation are always greater than what can be said about them. Participants are able to articulate only that portion of meaning that they can access through reflection. As Merleau-Ponty (1945/1962 cited in Polkinghorne, 1995) described it, it is as if participants are asked to shine the light of reflection into a well. The light only carries so far, and the well is deeper than the light can penetrate. This deeper portion remains in the dark and cannot be observed. Following each meeting

with a participant, through the application of mimetic theory, the different possibilities for engaging with meaning-making processes presented by the different types of activities in different environments also became apparent, as did the limitations. Again, it seemed important to capture this in the research text.

My approach to the narrative emplotment was guided by Polkinghorne (1995) who draws directly on Ricoeur's (1984) narrative theorising. Specifically, Polkinghorne considers narrative analysis to be a hermeneutic task; trying to grasp the interplay between the actions, the social context, and the interpretation of what is said or communicated in other ways. The procedure can be compared to the principles described in the hermeneutic circle, involving a back and forth movement between the parts and the whole. The process began with close reading of the field texts to try to comprehend each participant's story as a whole. Approaching the text, I asked analytical questions to understand how the participants negotiated and created meaning in relation to different events and experiences, and concerns, hopes, desires and possibilities connected to them. I was particularly attentive to the possibilities for participation and contribution, and the everyday practices of citizenship. I kept typed notes for each participant to capture any developing ideas, including lists of events that the participant had underscored as significant, plus events that struck me as significant and why they seemed significant.

Preliminary interpretations were drawn in an attempt to understand how different events contributed to the development of plots. Importantly, the story constituted by narrative configuration allows for the incorporation of notions of purpose and choice, both through their presence and absence, as well as chance happenings, dispositions, and environmental pressures. In this analysis, I attended to the temporal and unfolding dimension of human experience by organising the events extracted from the data along a continuum. I also looked at the welcome and less welcome possibilities that participants contemplated, and whether these were actualised within or persisted through the study period. I made use of post-it notes that I could move about, add to or remove. An example of these notes and a photo of my 'post-its wall' is provided at Appendix XIV.

The analytical process was not straightforward. Clandinin and Connelly (2000) highlight that it is in the construction of research texts and associated dialogue, imagined and desired, with the reader that narratives rub up against reductionist and

formalistic terms. The authors add that these terms are part of everyone's intellectual world. I found they were very much part of my world and at times it was tempting to think of the participants' unfolding stories simply as exemplars of structural categories such as gender or class (see Appendix XIV). Adding events and attending closely to the details caused these categories to fragment and enabled the nuances of different experiences to be preserved.

As each plot began to take form, the events and happenings that seemed most crucial to the story as a whole became apparent, with each event taking its meaning from its contribution to the whole. Not all events and data elements were needed to configure the narrative. Spence (1986) suggests that elements which do not contradict the plot, but which are not pertinent to its development, do not become part of the storied narrative, a process called narrative smoothing. In determining which events were and were not needed, I was keen to preserve not only continuities and concordance, but also some of the discontinuities, uncertainties and contradictions that were very much part of the participants' experiences. Each narrative is my interpretation and represents just one possible interpretation. Because of this, it was not appropriate to ask the participant to verify it as the 'real' or 'true' story (Polkinghorne, 1995).

Authenticity and Trustworthiness

Like all narrative researchers, I undertook this inquiry to have something to say to readers about the human condition. The knowledge claims produced are intended to be taken seriously. This requires provision of sufficient justification for the claims I make. Internal validity and external validity are key considerations in quantitative research, but the relevance of the concept of 'validity' in qualitative research is contested. Certainly, generalisability was not a goal in this study and is not the purpose of Narrative Inquiry. Equally, representativeness was not sought, but participant diversity was an aspiration and was achieved in part, as described in Chapter Six. Guba and Lincoln (1994) have developed alternative criteria for qualitative research, suggesting trustworthiness, authenticity and transferability are critical, as discussed below.

The use of theory to guide narrative analysis and interpretation provides scope, direction and concepts, and can enhance the transparency of research results. The provision of thick descriptions of the context and the way in which conclusions are reached, including reflexive accounts, should allow readers to critically reflect on and make judgements about the authenticity and trustworthiness of the narratives. The

question of 'authenticity' was at the forefront of my thinking throughout my time in the field as well as during the analysis and I offer an extended account of my reflections in support of this in Chapter Nine.

In judging the quality of a single narrative, a distinction should be made between the accuracy of the data and the plausibility of the plot. The evaluation of the configurative analytic work is based on the resultant narrative's explanatory power, namely the production of coherence among the situated, contextual, and particular elements of the data (Connelly and Clandinin, 1990). That said, the narratives are not intended to be too neat and tidy and Crites' (1986:168) cautionary phrase is to be aware 'the illusion of causality'; narrative explanation derives from the whole.

Unlike other forms of qualitative research where transferability of thematic findings to other contexts is a key consideration, with appropriateness of the transfer aided by thick description of the context, the evaluation of each narrative has a pragmatic dimension. Ultimately, the value of a narrative depends on its capacity to provide the reader with insight and understanding. Narratives function as arguments in which we learn something essentially human by understanding an actual life as lived (Clandinin and Connelly, 2000). This relates directly to Ricoeur's (1984) concept of 'refiguration' and the potential for revelation of what has previously remained unseen and unheard, in this case in the realm of the ordinary. It also holds the potential for transformation, through an invitation to act differently. I consider this potential in Chapter Nine. In presenting the narratives as a set, the main purpose of the subsequent commentary is to highlight differences and nuances among the cases (Clandinin and Connelly, 2000). Although striking similarities are also noted, paradigmatic analysis is inappropriate.

Reflections and Way Forward

This chapter detailed the methodological approach I employed in the study to facilitate an exploration of how everyday life with dementia is accomplished, drawing upon the narrative theories set out in Chapter Four. I considered the alignment of the selected methods with the principles and ethos of citizenship-as-practice. I also reaffirmed the central place of reflexivity within Narrative Inquiry and established the importance of trustworthiness, authenticity and analytical transparency. Mindful of the importance of transparency, and using the research questions as a guide, I present the results of the analysis in a way that 'shows my working'. Specifically, I describe the development of relationships with each participant in Chapter Six, together with the implications for

reaching understandings. To illustrate the different meaning-making possibilities presented by the different types of activity engaged in, I describe and interpret one particular experience of joining a participant or couple on the Narrative Inquiry landscape in Chapter Seven. I then present the five emplotted narratives which contextualise and expand upon these experiences in Chapter Eight, together with interpretations. Finally, in Chapter Nine I reflect upon the experience of doing the research, with a particular focus on the opportunities for meaningful participation and authentic engagement.

Chapter Six

Opening Doors: Introducing the Participants

Overview

In this chapter, I introduce the older people who took part in the study and describe the sorts of interactions and activities that took place when we spent time together. I also consider the implications of the different forms of co-participation for the development of our respective research relationships and for gaining insights into the situated and unfolding nature of each person's everyday life. The chapter thus lays the ground for the more interpretive accounts of particular experiences, the ongoing narratives and the implications for identity presented in the subsequent chapters.

As soon as I entered the field and each person or couple invited me to step through the door into their lives, my thinking changed. The 'research participants' that I had been desperate to 'recruit' became real people, and the 'diverse characteristics' that I had sought didn't begin to scrape the surface of their varied life histories or current situations. Clandinin and Connelly (2000:63) describe entering the field as 'beginning in the midst'. Just as I come to the inquiry field in the midst of my story, the participants enter the inquiry field in the midst of theirs. Or perhaps they are nearing the end. Their lives however do not end the day I leave and they do not begin the day I arrive. The places in which they live, the families and communities they belong and contribute to are also in the midst of their stories. As a narrative inquirer, I enter lives in motion, pre-narratives, the (re)telling still to come via the inquiry. In this chapter, I hope to convey a sense of this 'beginning in the midst.'

Distilling the uniqueness of any one person or couple into a short summary is of course reductive and challenging. The pen portraits that follow include the biographical details the participants emphasised to me during the fieldwork, together with the sense of their individual characters that I formed, through dialogue and interaction, during our initial meetings. Each pen portrait is followed by a brief account of the various interactions and activities engaged in, complementing the more in-depth and necessarily selective extracts and emplotted narratives provided in the subsequent chapters. In these brief accounts, I reflect upon the introductory meeting with each person or couple, and its role in setting expectations and influencing future research

undertakings. This includes consideration of motivation for taking part in the study, interpretation of 'everyday activity' and the extent to which this concept was discussed or problematised. I also summarise the key changes that took place within and outside of the research encounters during the study period and the implications for possible narrative configurations.

Research is relational and the quality of data generated and interpretations are predicated on the quality of relationships. I therefore explore the way in which each research relationship developed, including the importance of first impressions, sustained engagement, attending to previous experiences and the place of reciprocity. Finally, I draw conclusions about the sorts of interpersonal processes that proved crucial to developing and fully contextualising my understandings, bringing together my learning from doing everyday activities and developing relationships with the participants across the study as a whole.

Hector

Hector is a tall man in his early 80s who sports a thick mane of wavy silver hair. He appears physically fit, although quite a few health problems are alluded to. The biographical details that he is most keen to impress upon me are his previous inter-related interests in politics, travel and jazz. He taught himself to play the clarinet and tenor sax, enabling him to join the band when he did his National Service. Hector is at his most eloquent and relaxed when talking about former adventures and accomplishments, particularly those that required self-determinacy and initiative. He tells me that he is uninterested in the 'bland politics of today' and volunteers the information that he is an atheist. I learn that he has been a keen sportsman throughout his life and is the oldest playing member at the local golf club.

Hector is married to Gina, a small, bustling woman who he met at a dance hall when he was twenty and Gina was 'sweet sixteen'. They have enjoyed many shared interests over the years, especially their passion for jive, jazz and travel. Hector worked in one of the mills close to his parents' home when he left school and again following National Service, working '*from the very bottom up to the role of manager*'. He was later '*head hunted*' by another mill close to his current home, which he and Gina moved to nearly fifty years ago. About ten years after this move, Hector sensed that the mills were coming to an end and secured a place on a University course, enabling him to embark on a different career path in education, which he pursued until he retired.

Hector has made many alterations to the house over the years, which are a source of pride. The detached house is located at the top of a steep hill and is about a fifteen-minute walk from the nearest bus stop. It has a sizeable, sloping garden, which a gardener now maintains. Neighbours have come and gone and Hector doesn't know them well, with the exception of one couple directly opposite. Hector and Gina have one son, Chris, who lived abroad for many years, but recently returned to Scotland with his wife and family because Hector and Gina are '*getting on a bit*'. Chris's wife has since moved away with the children to be closer to her own parents and Chris is living with Hector and Gina '*for the time being*'. This development is described as '*very welcome*'.

Hector frequently refers to problems with his memory and becomes frustrated when he can't recall names of people or places. He repeats one or two anecdotes, and checks with me to see if he has already told me others before beginning. During our introductory meeting, he tells me he may not remember much of our conversation and that his memory is getting worse. When going through the consent process, after reading the text 'people with memory problems or dementia' he scores through the words 'or dementia' with a pen, saying '*I think dementia is a terrible word, it makes you think about someone gaga and drooling*'. Gina is more forceful in her rejection of Hector's diagnosis of Alzheimer's disease, informing me that his memory loss is due to an earlier urinary infection which resulted in a lamentable hospital admission. She insists that things are improving, emphasising that she '*knows him better than anyone*'. I learn that Hector was discharged from the memory clinic after three visits, once she '*cleared things up*'. As Hector recently resat his driving test and '*passed in the A category*' Gina has processed this as further evidence that '*his original diagnosis was clearly wrong*'.

Doing everyday activities together: 'Hoping to get the kick start I need'

Hector is the first person to contact me about taking part in the study. He is articulate and coherent when we speak on the phone and demonstrates a sound understanding of the nature of the research, telling me he thinks it will be mutually beneficial. Specifically, he understands that the research is in support of a PhD and suggests that helping me to complete this (rather than contributing to knowledge or helping unknown others) is his reason for taking part, regarding this as consistent with his former role in education. In terms of the benefits for himself, Hector tells me that he is withdrawing and recognises the dangers of staying in bed late or watching TV all day, but finds his motivation is waning. Hector's understanding of 'everyday activity' is

something that he should be doing more of and by taking part in the study he is '*hoping to get the kick start*' he '*needs*'.

I am excited about meeting Hector, but when I arrive outside his house I am intercepted by Gina whose first words are '*I don't think he's going to go through with it*'. She speaks hurriedly, but her key issue appears to be that the letter about the study and Hector's appointment to re-sit his driving test arrived at the same time. I am told that the driving test had been a source of anxiety and Gina has put the study letter in the same category. She tells me that Hector has been '*doing great*' since he passed the driving test, seems to think I am going to be '*testing him*' and that this will '*upset him*'. I stress that I don't want to upset Hector, ask if I can try to reassure her that there will be no testing, or if she would prefer me to leave. She replies that Hector is looking forward to my visit and goes ahead of me through the door, calling out his name and shouting '*that's Karen here*'.

On entering the house, I am assuming that Hector will not be taking part in the study. When I go into the kitchen, Hector is on his knees and in the process of defrosting the fridge. He looks up and the first words he says to me are '*you can help me with this*'. At first, I think he is joking, but Gina says '*let her take her coat off first*' and takes my coat from me. At this point I am wondering what I have walked into. I question whether Hector has understood the research leaflet after all and perhaps thinks I am there to help with household tasks. I also notice that Hector looks a bit dishevelled. This face to face encounter does not tally with the impression I formed during our phone conversation. I am mulling all this over when Gina says '*I told him not to be starting that when you were coming*' and Hector responds crossly that '*the whole point is that I just do what I would normally be doing*'. He asks '*is that right?*' and I agree, adding that there are a few things I have to chat through to check that the leaflet explains things properly, to answer any questions that he or Gina might have, and to make sure that he is happy to go ahead.

I note that Hector still thinks he is taking part in the study and try to think on my feet how best to manage the situation. Also, of all the '*everyday activities*' I thought I might end up doing with people, defrosting the fridge was not one of them. Hector has a pile of ice in each hand, there doesn't seem to be a receptacle for it and he seems uncertain what to do next. I ask if I can make myself useful, take the ice from him and empty it into the sink. For the next five minutes or so I help him to remove ice from the freezer

compartment while Gina looks on. It is a bit of a palaver and I warn them that I am no domestic goddess. When we finish I ask if they would like to have a chat about the research and Gina offers me a cup of tea, nodding and smiling, and I accept.

I am taken through to the living room and make small talk with Hector until Gina returns with a tray. When she says she'll *'leave us to it'*, I stress that it's important to know how she feels about Hector's involvement in the research too, still a bit thrown by our doorstep encounter. Gina tells me she thinks *'it'll all be fine'* and that she is going to sort through some washing and will join us afterwards. I chat with Hector for quite some time and detect a marked difference in his demeanour when talking about his past accomplishments versus the present day. He attributes his current apathy to the weather, but also tells me that part of the problem is that he has *'been everywhere and done everything'* and has no remaining ambitions. I remind him about re-sitting his driving test and how well he performed and this results in a lengthy account of the importance of driving to the golf club, which he still tries to do a couple of times each week to meet with friends, even if the weather is too bad to play. When he suggests that I accompany him to the golf club as part of the study, I say that sounds great and ask how Gina feels about him taking part. He goes off to find her.

When Gina returns she appears very animated, saying how much he's enjoyed my *'visit'*, adding *'and he's been telling you all about our jiving'*. At this point Hector grabs hold of her and they perform an impromptu dance. Suddenly I see a devoted couple that have been together ever since Hector plucked up the courage to ask a bubbly sixteen-year old girl to dance over sixty years ago, each trying to process the experience of ageing and memory loss in a different way. I reflect with shame on the uncharitable thoughts that I was entertaining in their kitchen a short time ago. When we discuss the idea of my accompanying Hector to the golf club and then taking it from there, Gina rubs her hands together and leans toward Hector saying, *'oh that would be good, wouldn't it'*. Before leaving, I follow Gina when she goes to get my coat to ask her about her initial concerns, but she assures me that she thinks *'doing the research will be good for him'*.

This initial meeting in many ways proves defining. It sets the expectation that Hector will be helping me personally, drawing on skills acquired through his former professional role. Gina's endorsement is based on her belief that taking part in the study may be good for Hector and she is *'happy for it to be Hector's thing'*. The research summary record for Hector is provided overleaf.

Table 6.1 - Summary Record for Hector

Date	Description
17/12/2015	Chilly start: Introductory meeting, consent process and getting to know each other after defrosting the fridge.
January	January blues: Series of telephone calls to try to arrange for me to accompany Hector to his golf club, but he has not been going due to snow or heavy rain and a series of health problems such as a leg strain and inability to hear due to ear wax.
08/02/2016	Retracing steps: Rather than making the weather dependent trip to the golf club we agree to meet at Hector's home and spend the afternoon chatting and sorting through memorabilia from his various trips abroad.
09/03/2016	Paying my dues at the golf club: I join Hector on his Wednesday lunch time trip to the golf club. A man in his mid-90's goes for lunch everyday with his son and Hector is one of a group of men who take turns to pop in on different days to provide them both with some company.
02/04/2016	The best medicine - meeting the boys at the golf club: I accompany Hector and his friend Bill on their Saturday trip to the golf club. I join a group of seven very companionable men and observe their use of humour to make light of their respective ailments.
02/06/2016	Sunshine after the rain: Hector is doing some light gardening when I arrive and I help him for a while. Gina has had a 'turn' at her keep fit class. She joins us and we spend the afternoon sitting in the garden as they chat about their forthcoming travel plans.
03/07/2016	End of the line: I had arranged to meet up with Hector to hear about his railway trip following the West Highland Way, but when I phone to confirm I am shocked to learn that Gina is seriously unwell.

Hector's desire to present himself in a favourable light persists when thinking about the ways we might spend time together and I tend to see Hector on his '*brighter days*', interacting with people he feels comfortable with. As the golf club plays a major role in structuring Hector's week, it also features prominently in the chapters that follow. Over the course of the study there are several call-offs, attributed to the weather or to Hector's health ailments, and these call-offs in themselves prove insightful. The study duration also means that I have the opportunity to observe Hector's mood change with the seasons. Then a dramatic change in Gina's health turns Hector's world upside down, bringing his involvement to an abrupt end.

Developing relationships: Old habits die hard

The development of my relationship with Hector is heavily circumscribed by our initial meeting. I find myself treading carefully to begin with, often slipping on my professional hat and drawing upon strengths-based conversational techniques.

Hector's own former profession is another important factor and he still enjoys educating people. He delights in sharing public speaking tips and words of wisdom, his traveller's tales inspire me to visit Nepal one day and he frequently repeats his life motto '*this is no rehearsal*'. I guess old habits die hard for both of us. When I observe his friends from the golf course jibing him for boasting or name dropping, this accentuates the entirely different quality of our own relationship, which maintains a distinctly inter-generational flavour. The nature of our relationship influences what Hector chooses to show me or tell me about his situation and how I respond, and thus shapes and informs my understanding. This is consistent with my aim of encouraging each person to guide the depth and breadth of our interactions, but Hector introduces me to the practical consequences of this aspiration. I try to keep sight of the nature of these choices as I document the inevitably partial understandings that I co-construct with Hector, and indeed with each person or couple, in the chapters that follow.

Tommy and Grace

Tommy is a highly affable man in his mid-80s who likes to talk! He is a bit of a joker who uses humour to field questions. Physically he remains very fit and is a keen walker. Tommy is quick to tell me that he never knew his father, that his mother died when he was just two years old and, most poignantly, that he has '*no memory of her*'. He was raised by his grandmother in the main, occasionally being '*passed round*' a series of aunts when he '*got too much for her*'. He later makes a point of showing me his birth certificate and mother's death certificate as if to confirm his account. Tommy tells me that he struggled at school and developed a bad stutter. He grew up in the countryside and despite descriptions of real hardship in his early life, particularly during the war years, he enjoys recounting tales of various scraps, scrapes and odd jobs working on the land. He sounds like a bit of a handful.

Tommy is married to Grace, who he refers to as '*the secretary*'. She is a delightful, softly spoken lady in her early 80s with a terrific (and necessary) sense of humour and an aura of calm. She strikes me as very capable and organised and although she enjoys a busy life, she doesn't share Tommy's love of walking and has a bad back. Grace and Tommy are active members of the local church and their faith is important to them. They grew up in the same rural community and met at a dance in the church hall. They have a son, '*number one son*' who '*has done very well for himself*' and lives with his wife about a thirty-minute drive away. Their daughter lives in a remote area with her

husband and it is suggested that '*their lifestyle*' makes visiting difficult. Tommy and Grace talk fondly about their several grown-up grandchildren, none of whom live locally. One lives in Australia and they keep up with the progress of his son, their first great grand-child, via skype and various phone apps, which Grace demonstrates that she has mastered.

Tommy was as a tradesman for most of his working life and Tommy and Grace moved to their current modest home almost forty years ago when Tommy got a job with the maintenance department for the council in the nearest city, finding the daily commute preferable to city life. The house is traditionally furnished, orderly and has a small, well maintained front garden and larger back garden, which Tommy insists he '*keeps on top of*'. Most of their neighbours have lived in the street for many years too, and they all look out for each other. Tommy calls one neighbour '*the Captain*' due to his deportment, and another '*the Sheriff*' as he '*has keys for everyone's houses and knows everyone's business*', but there is a fondness behind the jibes.

Tommy's memory difficulties do not seem to frustrate him and he compensates well through his use of humour. He speaks fluently and quickly, only occasionally searching for names of people or places, but has a tendency to 'jump tracks', reminding me of a scratched vinyl LP record. He accepts his diagnosis of Alzheimer's disease and tells me he knows it is there, but tries not to think about it. Grace has signed up with the Alzheimer's Society and finds the newsletters helpful. She and Tommy have taken advantage of tickets for the theatre, but when we first meet, she is disinclined to attend anything more dementia-specific.

Doing everyday activities together: 'Whatever's best for you'

When I meet with Tommy and Grace it is apparent that they have considered the study Participant Information Leaflet carefully and are keen to do '*whatever's best*' to meet my requirements, rather than raising their own concerns or restrictions. The fact that the leaflet was posted out by their GP has carried considerable weight, but they create the impression of people who enjoy exploring whatever opportunities come their way. Their understanding and enactment of 'everyday activity' is consistent with the examples offered in the leaflet and the concept is not contested.

Tommy is keen '*to be part of a study*' and demonstrates a good understanding of what the research will entail. He immediately asks me if I am a walker, telling me that he goes out for walks most days, so I '*best dig out my hiking boots*'. He reveals that he's

interested in history too, particularly of the area where he grew up and spent his early adult life, and suggests maybe I could have a look through his history books with him *'if the weather's not so good'*. His main social activity is a weekly men's group at the church, which *'of course'* I won't be able to attend. Tommy understands the planned duration of the study, telling me *'if you want to get to know all about me and what I get up to, it'll take you more than seven meetings'*. While at this early stage I am comfortable pointing to the description of the REC in the leaflet, emphasising that the Committee agreed to a maximum of seven meetings as this is a rather big ask, this is the first clue that I might need to remain alert to the sensitive management of ending Tommy's involvement in the study.

Grace demonstrates a firm grasp of the purpose of the different types of 'activity' that I had set out in the leaflet, and she is keen to help Tommy think of ways to satisfy the suggested mix of routine and more socially significant activities. I admire her no-nonsense approach when asking me questions about her anticipated role. I am also struck by Grace's pragmatism and discretion in helping to compensate for Tommy's difficulties. She informs me that there have been *'a few incidents'* when Tommy has been out and about on his own, but her approach is to find ways to manage risks rather than avoid them. For instance, when Tommy did not meet up with his son as arranged, resulting in seventeen missed calls, this was attributed to Tommy putting his mobile phone on silent as a result of being left-handed, and a new DORUS phone has since been purchased.

The summary record of my meetings with Tommy and Grace is provided in table 6.2 overleaf. All meetings take place as scheduled during the previous session, although Grace's involvement is reduced due to her own health issues. We establish a pattern where I go out with Tommy for a few hours, giving Grace some time to herself, and we generally come back to the house and spend time together chatting, pottering around or watching television.

Table 6.2 - Summary Record for Tommy and Grace

Date	Summary Description
07/01/2016	Introductions: Consent process and getting to know each other through a long chat with both Tommy and Grace in the lounge.
14/01/2016	Setting off on a sure footing ~ a walk in the snow: Tommy and I walk (quite a complex but clearly familiar route) to the church café, have a bite to eat and then get the bus home and spend time with Grace on return.
28/01/2016	Running errands: Tommy and I take the bus into town, go to the charity shop, post a parcel and buy stamps at the post office, drop off a repeat prescription at the GPs and go to the supermarket. We have a coffee in a new Italian café before catching the bus home and chatting with Grace in the lounge.
11/02/2016	Lost in the woods? Tommy and I walk to an old house of historical interest that is being renovated and he takes his new camera. We learn the route is cut off, forcing Tommy to make a spontaneous change to our plans. Time with Grace on return.
03/03/2016	Countdown: Tommy is finishing up in the garden when I arrive and we start off there before going for a short walk. On return we have an extended chat in the lounge with Grace and also watch a bit of TV together.
12/04/2016	Carved in stone, disappearing ink: I had planned to accompany both Tommy and Grace to Roslyn Chapel, but Grace is recovering from flu. Looking at the carvings together seems to prompt a very different type of conversation and I experience concerns about ending Tommy's involvement.
11/05/2016	Can we still be friends? Tommy and I take a tour of an old cove that he has told me about and then walk to a nearby café where we meet Grace for tea and cakes and talk through the study and ways of keeping in touch before wrapping up.

The resultant mix of activities enables me to be with Tommy and Grace as they sit together in the comfort of their own home, shrieking with laughter at Tommy's one-line quips while watching his favourite TV programme, *'Wanted Down Under'* or his improbable solutions to the *Countdown* conundrum. I am also privy to some difficult conversations about an uncertain future. I am with Tommy as he walks confidently along well-trodden woodland paths and the snow-covered streets around his home. And I am there as he negotiates getting on and off buses and as he takes pains to complete transactions in cafes, shops, the post office, chemist and GP surgery. These activities entail interacting with different and changing places, technologies, people he knows well, less well, is unsure if he knows or not, strangers, an extraordinary number of dogs and other situational elements. During the study period, a number of changes take place outside of the research encounters; some activities cease, the continuation of others is questioned and new activities commence, many directly related to Tommy's diagnosis. Together we generate a huge volume of material and the analytical

possibilities are potentially overwhelming, demanding transparency about the selections made in subsequent chapters.

Developing relationships: Breaking up is hard to do

Throughout the study period, Grace is very relaxed and open, and when I spend time with her and Tommy together I feel like a true ‘participant observer’. However, I am seldom alone with Grace, most of our one-to-one interactions take place by phone and often revolve around Tommy. This inevitably skews my understanding. In contrast, I spend a lot of time on my own with Tommy and the solitary nature of many of his interests means that I change the situation simply by being there. During our earliest meetings, Tommy does most of the talking, often at speed, jumping from one topic to another without pausing, skipping decades. I have read much about people with dementia struggling to keep up with the pace of conversations, but initially I find I struggle to keep pace with Tommy as he travels through time. I wonder what relevance much of the content has for the research purpose and even whether I should transcribe everything. I am glad that I do as I am able to piece together many of the different fragments and the significance of many of the biographical revelations later becomes apparent. Importantly, I am able to demonstrate to Tommy that he has been heard.

As the study progresses, the dynamic changes; the pace of Tommy’s talk slows, becoming more coherent, firmly anchored in what we are experiencing together, and the transcripts start to take the form of a relaxed, informal dialogue. Tommy often confides in me, I begin to feel that I know him, that we understand each other. I carry this understanding forward when interpreting the data presented in the chapters that follow. However, through this understanding I also realise that participating in the study has itself become a valued activity for Tommy and that I may be altering his future path. He tells me that meeting me is ‘*the best thing that’s happened*’ since his diagnosis. In turn, I come to care about him a great deal. It is Tommy who first alerts me to the parallel processes that are taking place in each of the research relationships, albeit in different ways, and to the reciprocal and ultimately mutual nature of the research endeavour. And it is my relationship with Tommy that raises the greatest number of ethical moments and that I become most anxious about ending. It is therefore my relationship with Tommy that I choose to focus upon in Chapter Nine as part of my reflection on the research methodology.

Jim and Mary

Jim is a very tall, quietly spoken and private man in his eightieth year who retains an athletic build. His father ran a small business and Jim helped out from a young age, then worked there full-time '*straight from school*'. He later went into business for himself against his father's wishes and, to his regret, they became estranged. Jim worked hard to build his business into a highly successful enterprise over the years, eventually selling up to a multinational company. In his younger days, a family friend sparked an interest in cycling and Jim became a cycling champion. This stood him in good stead when he did his National Service as he was able to continue training and competing. In later years, he became a low handicap golfer and proficient curler. He tells me that he loved sports and is '*paying the price now*' as he sorely '*misses the buzz*'. Upon retiring, Jim's business expertise resulted in numerous invitations to sit on various local committees. While his involvement has decreased in recent years, when we first meet he is still volunteering at a local stroke club that he helped to establish.

Jim met his wife Mary when she worked in the bank used by his father's business. Mary is small, very trim, physically fit and a keen sportswoman. They have a son who lives locally, plus a daughter and a son who both live further afield, but telephone frequently and visit when they can. They enjoyed staying with their daughter and her children for an extended period over Christmas. Jim and Mary live in a large, perfectly maintained home with a vast garden and while not isolated, there are no immediate neighbours. They have a few very good friends who visit quite often or they go to the golf club with for a bite to eat.

When we first meet, Jim has been diagnosed with mixed dementias and Parkinson's disease, but the latter is later revised to a more rapidly progressive form of Parkinsonism that doesn't respond to treatment. Jim doesn't have a tremor, walks stiffly but without shuffling, and while registered blind retains some blurred vision. He refers to his memory problems and has difficulty holding onto the thread of conversations, but is much more concerned about his '*tiredness*', as he struggles to keep his eyes open and often falls asleep. Mary has always enjoyed driving and initially Jim manages in and out of the car without too much difficulty. Her key concern is the frequency with which Jim has been falling. He had a bad fall the previous year when walking to the post office with her and broke his femur. This resulted in hospitalisation for two months, during which he declined significantly.

Jim remains fiercely independent. He had a particularly nasty fall in the shower a few days before our initial meeting, which has further rocked Mary's confidence and Jim admits '*it plays on me, mentally*'. Jim can no longer venture beyond the garden alone and while Mary will '*nip to the shops*', she can't leave Jim any longer than that. Jim attends a day centre twice a week and Mary has recruited someone to '*sit with Jim*' one additional afternoon each week until the end of the curling season.

Doing everyday activities together: Will your anchor hold?

When I first meet with Jim, he tells me that he struggles because of the lack of things he can do and that he is delighted to be doing the research because he '*feels useful*'. Mary adds that if they can help, why wouldn't they? Jim suggests that I '*can have open access*', but makes me smile when he asserts that '*the day centre doesn't really come under the category of day to day life*'; it is something he accepts as '*necessary*' to give Mary a break, adding '*I can't say I enjoy it*'. Although reluctant to complain because '*the staff are all very good people*', he will admit that he finds the activities on offer '*a bit unimaginative*'. He is also the first person picked up and last person dropped off and finds the bus journey difficult, particularly being '*strapped in*', '*driven all through the town*' and '*having to watch everyone struggle on and off*'. Due to his former prominence within the local community he also feels that everyone knows him, although he doesn't always know them, and finds this '*awkward*'.

In contrast, Jim is emphatic that '*the thing that helps most*' is volunteering at the stroke club each week, describing it as his '*anchor*'. Although he knows that he is unable to help the way he used to, he finds the club gives him a different perspective on life, particularly as many of the members are much younger than him, and it brings him '*down to earth*'. Having helped to establish the club, he also finds it '*very gratifying*'. Jim suggests that I accompany him to the club to '*see for myself*' what it gives him and, to Mary's surprise, he makes the necessary arrangements with the organiser. It transpires that this is to be Jim's last contribution to the club due to mounting concerns about him falling. Appreciating what the club means to Jim and experiencing the ending of his involvement first hand is critical in shaping my understanding of the overall situation. In the chapters that follow it becomes my anchor too. The summary record of my interactions with Jim and Mary is provided in table 6.3.

Table 6.3 Summary Record for Jim and Mary

Date	Summary Description
06/01/2016	Introductions: Consent process and getting to know each other
13/01/2016	Practice makes perfect: Walk to the post office with Jim and Mary as they practice a new hand grip suggested by the physiotherapist. Mary goes out to the shops and Jim chats to me while he potters around the kitchen and practices his chair exercises.
27/01/2016	Fault lines: I accompany Jim to the stroke club where he has volunteered for years; this transpires to be Jim's final input due to concerns about his frequent falls.
22/02/2016	Forever rescheduling: Mary phones to reschedule the meeting planned for the following afternoon as Jim has another medical appointment and she remarks that she is 'forever rescheduling these days'.
26/02/2016	Fish on Friday: Jim is late in getting back from the day centre, is very tired and uncharacteristically irritable. The customary Friday fish tea with friends has been called off and I keep things short.
30/03/2016	Still listening: Jim is finding talking very hard and apologises for being unable to keep his eyes open, insisting 'he's 'still listening'. I'm shocked to see how quickly his condition has deteriorated. Mary looks exhausted. Jim has had another bad fall and his GP has referred him to the day hospital, so it's 'now a waiting game'.
April-May	Waiting game: Over the months of April and May, I have eight phone conversations with Mary, which convey how prophetic the words 'waiting game' were. Each time she is waiting for an appointment date, to accompany Jim to an appointment, for news of results, about respite, from the hospital or finally about a care home placement.
06/06/2016	Filling the void: Mary phones to let me know that Jim has moved into a care home. She is buying him his own wheelchair as she finds him too heavy to push using the chairs provided by the home. She is accepting every social invite on offer as her life 'suddenly seems so empty'.
22/06/2016	Not the old Jim: Jim appears to have settled in. He is finding it very hard to talk or to open his eyes. His large athletic frame has bulked up a bit. He seems quietly content. Mary is struggling to cope with events and says often 'he's not the old Jim'.

Over the course of the study, I observe Jim and Mary's lives being increasingly structured by medical appointments and care services, then shattered by each successive fall. I spend time with Jim as he struggles to talk about how everything is slowing down, and ultimately when he is unable to say anything at all. In parallel, I observe Mary's daily occupation take the form of confronting the rapidity of Jim's decline and frantically searching for solutions. Along the way, 'everyday activity' takes the form of a waiting game.

Developing relationships: 'Not telling a very good story' – 'It's good to sound off'

My relationship with Jim is influenced by my first impression, his strong handshake, friendly welcome and broad smile. I instantly feel comfortable with Jim and sense an ability to put people at ease refined over his working life. I appreciate his dry sense of humour and he is aware of this. As Jim finds it difficult to talk or to keep his eyes open, I have to rely on my observations, intuitions and emotions. Jim has so much to contend with, yet never complains and exudes a quiet contentment. When we first meet, if Mary is present he defers to her but otherwise, if I wait, sometimes he will complete what he set out to say, other times he drifts off. Being with Jim, everything slows down, but I don't find the slowness awkward. What I get from being with Jim is a rare feeling of calm. Although I know that his thought processes are supposed to be slowing too, I get the sense that the effort it takes for him to speak causes him to think very carefully and prioritise what to say. When he remarks '*I'm not telling a very good story*', I respond sincerely '*on the contrary, I think you're making my job easier, doing a lot of the work for me, telling me only the most important stuff*'. Jim smiles, takes a deep breath and thanks me and I think we have an understanding. I like Jim enormously and I admire his graciousness and his candid reflections on life. He can be a bit stubborn, but is aware of his shortcomings as a man and seems able to accept them for what they are. For instance, he was a strict father who at times prioritised his business over family life, but acted for the best and in the only way he knew how. His favourite expression is '*in hindsight*'.

Then suddenly Jim disappears from my view – he is declining in hospital and all updates take the form of telephone conversations with Mary. My relationship with Mary is inevitably shaped by the dramatic nature of the events that she's experiencing. I am deeply concerned about pestering her when she has so much to contend with, but she says she is glad to receive my calls and also phones me several times. We often speak at length and she says '*it's good to sound off*'. The more obviously reciprocal nature of my relationship with Mary seems natural to me, forcing me to think again about the place of reciprocity within my other research relationships too. As our interactions are mediated by phone, they take the opposite form to those with Jim, with listening proving critical. In the absence of visual distractions, I find I can listen more deeply, hearing what's not said, feel her emotions. As with Jim, silences feel less pressured. I realise that this is a different but equally effective route to understanding.

It forces me to consider the possibility that perhaps when we have multiple communication channels available to us, we lose something.

Jim and Mary's involvement ends when Jim moves permanently into a care home. His condition has deteriorated markedly and conversation is no longer possible, but he continues to exude a quiet contentment. Mary draws comfort from this and from the happy atmosphere of the home. Nevertheless, I can't stop myself from howling. Perhaps inevitably, I find working with the 'data' generated with Jim and Mary an emotionally charged experience and am often paralysed by the weight of responsibility when making selection choices, configuring their narrative and advancing my interpretations.

Ann and John

Ann is in her eightieth year. She is a former teacher and one of life's '*good all-rounders*', having proved academically high achieving and sporty at school. When admiring a rather lovely mother and child painting, I discover that she is also 'an artist', although Ann thinks this description is '*rather overstating*' her abilities, adding '*an unstructured primitive at best*'. She looks exquisitely beautiful in the wedding photograph proudly displayed on the mantelpiece and is still in possession of a wonderful creamy complexion and captivating blue eyes. While her voice suggests privilege (she lived in India with her own Ayah when her father was a 'through the ranks' major in the army), her early life was also characterised by trauma (narrowly escaping by boat during the fall of Singapore), upheaval (frequently changing school and attending several detestable boarding schools) and hardship (when her father retired and, unable to commute his pension due to ill-health, the family moved to a house with an outside privy and no electricity on a smallholding in the English countryside).

Ann is married to John, a highly personable and intellectual man who she met through the University Maths Society during her fresher's week as John was commencing his final year. Ann and John openly demonstrate a rare and genuine devotion to each other. They have five very successful and supportive children, and fourteen diversely talented grandchildren. I am informed that their children say they have always thought of Ann and John as 'a unit' and I quickly find myself doing likewise. They make initial contact about the research using a joint email account and the email is also signed jointly. There is talk of old shared friends from their university days, now deceased or in rather poorer health than Ann and John and so seldom seen.

'Ann and John' now live downstairs in their large, cluttered family home, which has an absent-minded professor quality to it and at first, I suspect that it has remained unchanged for the last fifty years. In fact, this is only partly true, and I discover that John has been recovering memorabilia from trunks in the attic and distributing them through the various rooms in a bid to conserve Ann's memory. This is something he also strives to achieve through nostalgic holidays, road trips to old haunts and extended family gatherings, plus everyday conversations, often looking through photo albums. When Ann said to John "*I can't now remember the unforgettable time when we first met*" John set about typing up his account of how they met and fell in love, a copy of which is taped to the inside of their wedding album. This undergoes constant revision as a result of his conversations with Ann. (John emails me a copy of each version). He is also trying to rekindle Ann's more aesthetic interests, particularly gardening and painting, but to no avail. Ann now walks with a stick, is unsteady on her feet and I am informed that she has had '*one or two tumbles*'.

Ahead of our introductory meeting, John emails me to say:

'Ann and I have just re-read your research description, with an immediate reaction on her part that "I don't have Alzheimer's" which, given the sharpness of her mind in several directions, is a justifiable statement; she is willing to accept the memory loss aspect while pointing out that my memory is not always as secure as it might be... She is quite resolute about this and I seldom press the issue, except when she berates one of our daughters for meddling'.

The sharpness of mind that John refers to is immediately evident and Ann demonstrates a particularly impressive retained capacity for critical thinking. In the past, Ann has found medicine over-reaching and demonstrably fallible (e.g. she refused a prescription for Thalidomide when expecting her second child) and I interpret her rejection of the Alzheimer's label as consistent with this mode of thought. John has prostate cancer, an intermittent stomach complaint and experiences chronic hip pain. Despite their respective '*depredations of old age*,' they are content. Sitting alongside each other in their matching Riser recliner chairs, Ann is a delightful, fluent, articulate and extremely quick-witted conversationalist, with John ever-ready to supply ever so subtle cues.

Doing everyday activities together: Searching for the 'apposite word'

When I first meet with Ann and John they are very keen to help with the study if they can, but wonder if they will be '*suitable*'. During my tour of the downstairs of the house, John reveals that Ann really '*doesn't do anything now*', apart from making the occasional

cup of tea, which he then carries through on a tray. She will very occasionally help John with simple tasks such as folding laundry, but quickly loses interest. Ann is quite content to have visits from the family or to sit and *'talk about old times'* with John. However, she does not seem to be aware how much John is doing. John admits he *'rather misses her contribution'* and gets very tired, but *'simply couldn't bear outside help'*.

Ann asks me directly about the reason for my *'particular interest in activities'* and when I state that I don't really mean activity in a physical sense, she responds *'oh, what do you mean?'* Good question - and an interesting discussion ensues. Ann agrees with me that switching to *'how you spend your days'* or *'pass the time'* sounds terribly passive or possibly insulting. *'Coping'* is suggested, but Ann quickly argues that *'it rather presupposes not coping, or that there's something that has to be coped with. There's something slightly negative about it'*. She offers *'managing'*, adding *'that's not quite right either - negotiating perhaps'*. John then comes to the rescue by reaching for the dictionary. He reads out the definition of coping as *'to deal with successfully'* and we conclude that *'dealing successfully with the daily round in later life'* best encapsulates my research interests. Thus, the tone is set for our future meetings.

Each meeting takes the form of *'chatting in the small sitting room'*, but despite its seemingly passive connotations, Ann and John have developed a distinctive style of *'chatting'* that blends mutual support and challenge. This encompasses gentle teasing, shared reminiscence, playfully provocative life review, fiery intellectual debate, discussing the study's progress and *'actively searching for the apposite word'*, as summarised in Table 6.4 below.

My understandings develop on the basis of co-participation in Ann and John's interactions with each other within the confines of the small sitting room, their accounts of events in the outside world and the occasional opportunistic encounter with a family member, nuisance caller or delivery man, yet there are very strong temporal and cultural transactions. Over the study period, inevitably some changes take place outside of our encounters and John sends me regular words of encouragement by email.

Table 6.4 Summary Record for Ann and John

Date	Summary Description
13/01/2016	Introductory meeting: Consent process and getting to know each other. Extended conversation about the meaning of 'activity' before agreeing that meeting at their home will be just fine for study purposes
20/01/2016	Every picture tells a story: Spend the afternoon looking through old photo albums and chatting about the past and how it relates to the here and now.
26/01/2016	Phone call: to reschedule our planned meeting on the 4 th Feb as they will be travelling down south to attend a friend's funeral.
10/02/2016	Managing expectations: Discussion about trip south, changing family dynamics, the importance of family unity and how their hopes for the future have been displaced onto their grandchildren.
02/03/2016	Good fortune and making vows: We explore the role of 'luck and happenstance' in life, particularly their good fortune in their own parents and their youngsters and the importance now attached to their wedding vows.
06/04/2016	Place integration: John has been sorting through some old letters he exchanged with a mutual friend and is sharing the contents with Ann. There is extended discussion about the effort of ageing in place, including dealing with nuisance calls, technology and the saga of the matching Riser recliner chairs.
05/05/2016	Phone call: During my customary courtesy call ahead of our meeting John advises that there has been a shift in Ann's condition in that she can become disoriented when he is not in the room.
06/05/2016	A series of surprising developments: Interesting and far-reaching conversation. The meeting follows on from John's birthday party, a rather exhausting affair that has caused a rethink of Ann's 80 th birthday plans and travel plans later in the year.
11/07/2016	Wrap-up and thank you meeting ~ I bring cakes, John has made biscuits and cheese

Developing relationships – We feel that we've known you for years

From my very first meeting with Ann and John I feel quite at home. They are incredibly welcoming, delightful company and truly interested in the study. As with Tommy and Grace, when I spend time with Ann and John together I feel like a true 'participant observer', I am sure that there is no pretence on their part and I also feel that I can be 'myself'. Indeed, it is the one setting where I find the 'different selves' that the researcher takes into the field most integrated. They tell me *'it feels like we've known you for years'* and I feel the same. That said, their devotion to each other is such that I feel reassured that I am not altering the situation unduly by being there (although John sends me some rather lovely personal correspondence suggesting their involvement has had positive affects).

That I spend little time alone with either Ann or John introduces some limitations, but as I am concerned with the situation as a whole and the various relationships at play,

rather than individual perspectives, this is less problematic. Moreover, it is Ann and John who are directly responsible for my raising the significant amendment with the REC to extend formal participation to the spouse or family member of the person diagnosed with dementia, discussed in Chapter Five. They are also responsible for my foray into the literature on 'couplehood' and in the following chapters, I relate to them very much as a couple, engaged in an enacted togetherness, their narrative co-constructed.

Chrissie

When Chrissie answers the door, I am immediately surprised, as she looks much younger than I had anticipated. She is wearing skinny jeans, a pink mohair jumper, blue pumps, silver dangly earrings and matching necklace, has her blonde hair cut in a modern style and sports a pair of trendy Gok Wan glasses. She also seems incredibly youthful in demeanour. She informs me that she has arthritis, but she is very bubbly and from the way she darts in and out of the kitchen and swings her feet as she sits on the sofa, you would never know. I am genuinely astonished when she tells me that she is 78.

The fourth of nine children, Chrissie recounts a tough upbringing, which she thinks it's important for me (and the reader) to understand. Her mother left home when she was four and was quickly replaced by a step-mother. Chrissie later discovered that her dad was not her real dad, *'so I wasn't related to either of my parents'*. In her early teens, she learned that her birth mother had died and she used to spend her weekends *'raking through the cemetery looking for her grave'*. When she eventually found the small, plain stone (now in her garden) she thought *"is that all she was worth"?* As soon as she could afford to, she replaced it with *'a beautiful big white angel – that's how I used to imagine her'*.

Chrissie's own domestic life has been equally troubled. She married young, her husband had a drink problem and her married life was a catalogue of domestic violence. She got divorced, remarried *'too quickly'*, had a few happy years, got divorced and later got back together with her first husband, which was *'a mistake'*. She came home one day and found him dead on the floor, but swiftly adds that she *'wasn't sorry'*. When I say to her that it sounds as though she's had some tough times, but looks remarkably well on it, she replies *'oh, but there have been some great times too, lots of laughs, and more good times than bad. No, I've been very lucky. Life's what you make it'*.

When we first meet, Chrissie lives alone in a terraced house in a former council housing estate, which is furnished in a very modern style. Three of her *'great neighbours'* are in their 90s, and she delights in recalling how she put balloons and banners up to mark their 90th birthdays and *'had a wee party for each of them'*. Chrissie has three children, eleven grandchildren and six-great grandchildren, *'all less than a stone's throw away'* and she stresses that they are all *'really close'*. *'We've all had our share of heartache, but it's kept us together'*. This heartache includes the death of a son to alcoholism when he was in his late twenties. When I say that I'm so sorry, she tells me directly *'if I could wish him back to life, I wouldn't'*. Chrissie worked as nursing assistant in what she refers to as a *'mental hospital'* for most of her working life and absolutely loved it. Her daughter has a few cleaning jobs and Chrissie helps out with a couple of the bigger houses for *'a bit pocket money'*.

Chrissie fully accepts her diagnosis of Alzheimer's disease, but adds that she tells people *'on a need to know basis. I'm not advertising it'*. She informs me that she is on Aricept¹⁵ and that it must be working as her *'scores haven't really changed much'*. Her son noticed that something wasn't right early on, *'he just came out and said to me, I think you've got Alzheimer's'*. She adds, *'but I knew myself'*. When she went for tests, the doctors said *'let's leave it for six months and see'*, but her son said *'look, we all know she's got it, she knows, she doesn't need time to get used to it, and in six months she'll be worse and you won't be able to undo it, so let's just start it now'*. She goes on to say that she is very glad that she did, as her brother had Alzheimer's too, but he was *'too far gone'* for the medication to make a difference and died three years ago. He was *'really bad at the end, so I know what could be around the corner'*. Chrissie adds *'there's no point worrying about the day that might never happen. A lot of worse things could happen, like the twin towers. All those folk, going off to work and never getting to say goodbye to their families. That's cruel. No, there's worse things in the world than Alzheimer's'*.

Doing everyday activities together ~ you won't make me feel like a performing monkey?

When Chrissie first contacts me to say that she's interested in taking part in the research, she adds that she isn't sure that she'll be suitable. Specifically, whereas Ann and John questioned their suitability due to Ann's lack of activity, Chrissie advises *'I have Alzheimer's, but I'm still quite good'*. We discuss this when I meet with her and she

¹⁵ Aricept is the trade name for Donepezil, a commonly prescribed medication intended to slow the progression of AD

explains that she thought maybe I was looking for people who were worse than her, because she can still do most things. She goes on to say *'the leaflet says things like tidying up and gardening, and I can do that no bother. Like I just steam cleaned my hall carpet yesterday. But then it says shopping and I thought well that is a problem, wellit can be'*. She immediately goes on to tell me about various problematic experiences at the supermarket, concluding *'so maybe that's something you know, where I'm not as good as I like to think I am, where I probably make mistakes'*.

I am struck by the reference to 'making mistakes' and explain that I wouldn't be looking to see how well she is performing. I add that it is more about all the stuff that she is doing, the things that matter most to her day to day, and what makes things a bit trickier, drawing on her own examples. After a long pause Chrissie says. *'I think that's good. I mean I can see how it would be useful'*. She adds *'what you said about performing, see you've been listening to me, but when I tell this sort of stuff to my consultant, he just says 'I know, I know'. He doesn't listen'*. Chrissie then tells me that she said to him at her last appointment *'No, you don't know, you don't know what it's like. You haven't got a bloody clue. How could you? If you knew, you would not make me feel like a performing monkey'*.

Having established that I will not make Chrissie feel like a performing monkey, we discuss the sorts of things that we might spend time doing together. She says she's *'not short of ideas'*, but most things she does with other people and she will need to check it out with them first. She is also very clear about *'just seeing how we get on'* rather than thinking too far ahead, and *'not letting it take over my life'*. When I ask about checking things out with her family she says, *'Oh you'll meet them, you'll meet all of them. If you spend any time at all with me, they're never far away'*. And indeed, they are not! The summary table of my interactions with Chrissie is provided in Table 6.5 overleaf.

The mix of activities that we engage in enables me to spend time with Chrissie as she takes the scenic route to avoid traffic and tries to find a parking place where she will see her car when she returns. I observe her as she negotiates transactions in the leisure centre and in various cafes and shops, including witnessing a masterclass in returning damaged goods. Yet it is the 'hanging about' at home with Chrissie that is most insightful. I experience the incessant phone calls, the requests for help and advice, her 'in and out' interactions with family members, friends, friends of friends and unknown others and I come to see Chrissie's role in their lives. I am there when she cleans, sweet

talks the boiler repair man, makes soup for neighbours, replenishes their planters, fills Christmas boxes for Africa, bakes cakes for the school fete, secures a good home for puppies and gives shelter to a homeless girl. Over the course of the study period, I begin to discern patterns and rhythms in what I initially perceived to be a chaotic lifestyle and to understand the significance of the stars on Chrissie's calendar. There are distinctions between term-time and school holidays, mornings and afternoons, and it is these distinctions that I focus upon in the following chapters.

Table 6.5 Summary Record for Chrissie

Date	Summary Description
24/02/2016	Introductory meeting: Getting to know each other and consent process – boiler repair man arrives one of her younger grandsons pops in with a pal and offers some suggestions
30/03/2016	Piccadilly Circus: Selling puppies, offloading wardrobes, receiving phone calls and various family members and friends come in and out. Chrissie tells me it's always like Piccadilly Circus
05/04/2016	Sink or swim: Meet Chrissie at home, we drive to her aquarobics class, spend some time in the Jacuzzi /steam room and then have coffee back at her house where she receives several phone calls.
21/04/2016	Everything changes: Spend time in the garden, go to the shops and then go to the garden centre. Back at her house I help to put her settee covers back on and her son pops in to borrow the Hoover –conversation around changing family and neighbourhood dynamics. Her daughter is moving in.
20/05/2016	In for a penny: Trip to the sports shop and the pound shops to get some stuff for the Christmas boxes and then go to a café. Phone call from an acquaintance who needs Chrissie's advice on selling a pram – she says 'I'll come'
15/06/2016	Open house: Chat to Chrissie as she packs for her holiday in Turkey – a homeless friend of her grand-daughter will be staying while she's away. She'd been out in the pouring rain earlier to buy a huge a cream cake for me. She's looking after one great grandson who is off school and pops in to see her nonagenarian neighbor, Elsie, with a cake.
16/08/2016	Bargain hunters: Drive to nearby town to have a 'rake round the charity shops' then go to a café to wrap up and say thank you. Back at her house we sort through her cake decorations and a few family members pop in.

Developing relationships – There for the long haul

My relationship with Chrissie is undoubtedly the one that grows the most over the study period. Initially I expected that I would struggle to relate to a person whose life differed so markedly from my own, but that has not been the case. For that Chrissie must take full credit. She is neither boastful nor modest, but tells it like it is and she's smart. She has a completely different set of priorities to me and different expectations. She does not conform to any of the established theories of ageing, but she has her own

'rules'. She doesn't take herself too seriously. She is the most generous person I have ever met, yet is no soft touch. Her concept of 'family' differs from mine, but her 'family' absolutely adore her and she would do anything for them. There is a lot of laughter in her life, a lot of parties and a lot of love. Over the study period, she smashes many of my middleclass assumptions - and she knows this. There has also been a shift in Chrissie's relationship with me. While she was staggeringly open about various tragic events in her life from the outset, they were relayed in a very matter-of-fact way. Her willingness to show me a chink in her emotional armour was deferred until our later meetings. This relationship and the resultant understandings unquestionably benefited from my being there for the long haul.

Reflections and Way Forward

This chapter introduced the unique persons who took part in the study. Their diversity presents opportunities to explore the implications of the different place that dementia occupies within their lives and in particular situations. The chapter also considered the different understandings of 'everyday activity' at play, plus the implications of the different forms of activity desired, available, imposed, discounted or denied and those the participants were willing or able to share with me. The fieldwork took place between December 2015 and August 2016. When it commenced there was a thick carpet of snow on the ground and it concluded on a warm summer's day. Being able to experience seasonal variations and key calendar events introduced further possibilities for enriching my understandings, as did simply being there through the passage of time. I look closely at one particular encounter in Chapter Seven and present the narrative that unfolded over the course of the study in Chapter Eight.

The different types of interactions and activities experienced with each person or couple were circumscribed in various ways and also spoke to the nature of our relationships. Each relationship was qualitatively different and developed in a different way and at a different pace. This difference went beyond making the study arrangements sufficiently flexible to acknowledge the varied abilities and distinctive preferences of the participants, requiring trust, attentiveness and responsiveness at the outset and in the small moments of doing (Stern, 2004). The contribution of each participant was significant and is duly acknowledged.

Spending time together over several months helped to strengthen our connections and the type of relationship developed depended in part on the sorts of moments enacted and experiences shared together. Being permitted to share emotionally heightened situations perhaps unsurprisingly brought closeness, but more unexpectedly, familiarity and understanding were also achieved as a result of experiencing the more mundane aspects of people's lives with them. The degree of closeness achieved varied. Quite apart from my wishes on the matter, participants sometimes draw the researcher in and sometimes hold her at a distance (Bateson 1994). Closeness, where present, served to increase the profundity of our conversations, the depth of my observations and my understandings. It also raised issues of boundary management and the nature of reciprocity. I reflect upon these relational issues in Chapter Nine.

Chapter Seven

Walkways: One Day on the Narrative Inquiry Landscape

Overview

In the previous chapter, I introduced the people who took part in the study and gave an overview of the various activities that I undertook with them. In this chapter, I provide a more in-depth account of one particular experience of ‘walking’ out onto the Narrative Inquiry landscape and spending time with each person or couple, following their lead along the ‘walkway’ through everyday life that they chose to share with me. Like a geographical landscape, the narrative landscape is familiar to the participants, well-trodden, but unknown to me. I try to strike a balance between following their lead and staying curious, without steering them into areas of particular interest to me.

Each initial description takes the form of an extract from field notes recorded immediately afterwards, documenting issues encountered in the flow of actions and the naturally occurring conversations that took place. In broad terms, each extract describes the enactment of an activity that the person or couple identified as important to them, giving structure and meaning to everyday life. A more nuanced rationale for the selection is offered in each case. The actions and the concurrent dialogue open up communicative and interpretative spaces and each description is followed by an interpretation, drawing upon narrative theory. The theoretical perspective facilitates an interpretation as to *how* meanings are configured and connections between past, present and future forged in the flux of actions, engaging with envisaged possibilities, welcome and less welcome. I conclude the chapter with some summary reflections.

Tommy and Grace: A Walk in the Snow

The time I spend with Tommy and Grace together generally takes the form of conversation in their living room. In contrast, I spend time ‘alone’ with Tommy engaging in diverse activities in multiple settings. When it comes to selecting a particular experience, the process is made easier as, from the outset, Tommy emphasises the importance of walking (literally) in his daily life. Of the many walks that I take with Tommy, our first best illustrates the familiarity of the routes around his home. It also surfaces a plotline that develops over the course the study and that I expand upon in the next chapter.

Uncharted territory

It is a beautiful, crisp morning and a thick blanket of snow has transformed the landscape. I am due to accompany Tommy on one of his daily walks and as I drive to Tommy and Grace's house I note that all street names are obscured, the boundaries between the roads, pavements and gardens concealed. Tommy is finishing clearing the driveway when I arrive, having made sure that he'd cleared the snow from the stretch of pavement in front of the house before setting off. We go inside and chat with Grace, who is expecting some visitors to discuss the Church Malawi fund. It is proposed that I accompany Tommy on a walk into town, refuel in the church café and catch the bus back. Before we set off, Grace ties Tommy's scarf and tucks it inside his jacket, insists he wears his woolly hat and checks that he has his phone, bank card and bus pass. She discreetly lets me know that Tommy remembers his pin number, but now finds using cash too confusing and makes sure I know which buses we can catch.

You just put your coat on and go

I follow Tommy as he's takes a complicated but clearly familiar route, trudging through wooded short cuts, carving our own path in the thick snow. I sense that Tommy could do this walk in his sleep. I learn that the house's proximity to woodland was a key factor in the decision to move there nearly 40 years ago, and although he *'still misses living out in the country'*, being able to go for a walk every day is *'a big compensation'* and does him *'the world of good'*. Tommy tells me that he has *'always gone out in all weathers'* because he and Grace were dog owners. They thought about getting another one, *'an older dog obviously'*, when their last dog died a few years ago, in the end deciding not to. He concludes:

'Some folk that have this thing that I've got, they just sit in a chair staring at the TV all day, maybe they cannae help it. If Grace is watching some of that rubbish she likes, I'll say to myself, get your coat. You don't need a dog as an excuse, you just put your coat on and go'.

Giving up the driving

As we walk, Tommy tells me various stories about his life, jumping from one era to another. The stories are fascinating, but unrelated to the 'real-time' context. Although mostly depicting hard times, they are recounted fondly. When we pass an isolated row of buildings, now home to a tanning parlour and small gym, he reconnects with the scene, telling me *'there used to be some nice wee shops there'*. I'm informed that the shops were the only option when he and Grace first moved to the area, but eventually the supermarkets forced them to close. He remarks *'they'd be right handy now that I'm*

giving up the driving' and I discover that Tommy has decided not to re-sit his driving test. He has heard that you have to park inside the white lines of the narrow parking bays at the supermarket and *'if you even touch the line you fail'*, so he's not going to bother because he *'was getting too uptight about it'*.

As we continue, I learn that the decision to stop driving has been made easier as he *'can walk most places'*, the *'bus stops right outside our door'*, he and Grace have always taken the bus into the nearest city, and *'the Sheriff'* and *'number one son'* have offered to drive them to appointments. However, although there is a good bus service to the supermarket, they are limited in how much they can carry as *'Grace isn't supposed to lift anything because of her back'*. Tommy tells me:

'We were going to sell it (the car), but Grace is going to give it a go... She's murder to be truthful hen, but I'm just ... making all the right sounds let's say, because she's lost her confidence. She used to drive all over the country selling Tupperware, but once we stopped working, I did all the driving... She was a good enough driver, it's just the way it happened'.

I'd have been none the wiser

Tommy immediately goes on to recount an anecdote that he repeats several times:

'And if I hadn't gone to the doctor I would have been none the wiser. I went, nothing to do with what's going on in my brain, but I must have said something strange because he brought out a wee piece of paper and asks me, 'do you know what date it is'? No idea. 'The year'? Not a clue. Anyway, four crosses. He says 'we'll see you again' and when I went back, I didnae remember what we'd talked about. So, I get sent for tests, they get me drawing all sorts, then an x-ray, no, what's ... the thing, och when they put you in the sexy box'?

Me: *'An MRI scan'?*

'That's the boy, the box of doom! Anyway, was a woman I saw, very nice, and she says to me what it was I had. And asks 'so how do you feel about that'? And I says, well I feel like a sixteen-year old. If I hadn't gone to the doctor I'd be none the wiser'.

The driving's just the start

When I ask if he would have preferred to remain *'none the wiser'*, Tommy thinks about this before saying *'well, she shows me a picture of this thing that I've got and says 'see it's there, but it's no too bad'. Tis but a touch of frost, aye'*. He adds that he's been told the medication is *'slowing it down, so maybe best to know, but...* He goes on to explain:

'Well the driving's just the start...Once they've gotten hold of you. Back and forth...more tests. The full works... you never know what they'll find next... I'm trying to put it to the back of my mind, hen. No use worrying. God's looking out for me. But, dare say, I mean... if they keep at it long enough... they'll find something else'.

He's lucky he has a wife who will look out for him

When we get back to the house, Grace is upstairs on the phone and Tommy rummages through the sideboard for some photographs he wants to show me. Grace comes downstairs and explains that she was talking to a friend whose husband has Lewy body dementia. She reports that *'he's been having terrible hallucinations, and getting all sorts of ideas'* and recounts the conversation, which sounds like a catalogue of mismanagement. She concludes by saying that her friend has finally managed to arrange for someone to come and sit with him for a few hours, because *'obviously he can't be left with just anyone'*. Tommy says to me *'you'll be right glad you stayed to hear that cheery tale.'* Grace adds, *'He's lucky because he has a wife who will look out for him'*. She goes on to compare his situation with another friend who has dementia and who is now in a care home because *'his wife died a few years ago'*. Tommy looks glum and says nothing.

Interpretation of 'A Walk in the Snow'

The above extract begins with Tommy clearing the snow in the vicinity of his house before going for a walk, consistent with his commitment to being a good neighbour and thus living a good life with and for others. Tommy grew up in the country and feels at home walking in the woods, connecting him with past times. As a responsible dog owner, he previously had to walk in all weathers, establishing walking as a habit that, over time, has been reinforced as beneficial; Tommy walks daily because it does him *'the world of good'*.

More recently, walking has assumed a new function, providing Tommy with distance – from rubbish TV and from *'other people who have this thing that I've got'*, but who *'can't help'* but sit and stare at the TV. In Ricoeurian terms, Tommy's power to be is manifest in his power to do. Tommy rehearses different possibilities in his imagination, entering the kingdom of *'as if'*; if he can continue his daily walks, he can maintain a distance from the image he holds of a person with dementia; an image perpetuated by dominant cultural representations. This possibility is facilitated by Grace, but it comes at the price of a new activity, *'checking'*. Grace checks that Tommy has everything he needs and Tommy submits to this; Tommy walks and Grace endures the uncertainty this brings. They are both active and passive.

The extract also underscores that the walk into town is so familiar to Tommy that the masking of the usual boundary lines by the snowfall presents no difficulties. Consequently, for some time the *'actual doing'* of everyday activity does not *'generate*

authentic dialogue... embedded within the flow of actions, as predicted by Alsaker et al (2009:131). Instead, the small stories¹⁶ Tommy recounts are divorced from the 'actual doing' of walking; they are complete, purposefully configured or selected from a practiced repertoire with a particular audience (a researcher) in mind. Few convey personal accomplishments and my impression is that Tommy is keen to convey that he has led a hard, eventful but good life and has lots of stories to tell.

On walking past a row of former shops, Tommy reconnects with the immediate surroundings and switches narrative modes. Through the lens of mimetic theory, in the course of doing one concrete activity (walking into town), images of another everyday activity (shopping) are created, setting in motion a chain of connections with past experiences and future possibilities, stirring the ongoing *mimesis* and connecting with Tommy's situation as a whole. A potential storyline is verbalised and constituted through communication with me; things could have been different, if not for people's preference for supermarkets. This in turn conjures images of going to the supermarket and the future alternatives that must be considered as a result of Tommy's decision not to re-sit the driving test. This narrative ending is up for grabs. The possibilities imagined and communicated include taking the bus; this is feasible because of an earlier decision to buy a house with a good bus service, but now presents its own difficulties, for Grace if not for Tommy, emphasising their interdependence. Another option is to become a passenger, generating a need for Grace to re-learn how to drive. This possibility displaces Tommy's anxieties onto Grace, requiring Tommy to assume responsibility for restoring Grace's confidence. Here again, the situation could have been different, if Tommy had not formed the habit of '*doing all the driving*', a habit deemed the right thing to do by men of Tommy's generation and class.

In the course of communicating these events to me, the image of parking between the lines at the supermarket introduces into the nascent story an activity that is playing an increasing part in Tommy's life – 'testing'. Tommy's anxiety about re-sitting his driving test, with its exacting requirements and risk of failure, forges a connection with the '*four crosses test*' that culminated in his diagnosis. If not for this test, he would be '*none this wiser*'. Tommy is confronted in a concrete way with another competing storyline, one pertaining to a health system that has '*gotten hold of*' him and appears to

¹⁶ I incorporate elements of the 'small stories' (Bamberg, 2004) that Tommy chooses to tell in the next chapter

have the power to determine what is wrong with him and apply a label of otherness, irrespective of how well he is feeling. In this unfolding narrative, Tommy has limited authorship, yet he anticipates the ending – eventually the testers will find something else and in so doing will further restrict his everyday activities; *the driving is just the start*.

Finally, Ricoeur's (1984) concept of 'distanciation' facilitates the following interpretation of the scenario that unfolds when we return to the house. A phone conversation with a friend offers Grace an opportunity to talk about issues relating to the caring responsibilities of a wife at a distance, using the stories of others as a safety filter. Her friend's situation is similar to her own, but not the same – Grace emphasises that the man has a different form of dementia than Tommy. Through the vehicle of her friend's situation, she is able to express anxiety about her own future and anticipate the demands of caring. In considering the alternatives, Grace first communicates to me, a researcher, that the future could be different if better support were available to women whose husbands have dementia. She then connects with the situation of a second set of friends, expressing strong emotions about their different fates. By asserting that the second man would not be in a care home if his wife were still alive, Grace conveys that she expects to look out for Tommy 'til death do us part. 'Distanciation' establishes an interpretative space where both Grace and Tommy can try out images of relevance and also contrary to their own experience. Tommy's reference to '*this cheery tale*' followed by an uncharacteristic silence may suggest that he is contemplating a plot where he, a man who has done all the driving and clears the driveway, becomes increasingly dependent on Grace. *The driving is just the start*.

Hector: Meeting the Boys at the Golf Club

When I first meet with Hector, he tells me that he goes to his golf club a couple of times each week and it is his primary source of motivation. However, he cancels planned outings to the club several times, attributing this to the weather or various health ailments. Although he goes to the club to meet briefly with an older man called Hamish and his son one Wednesday, he remains disinclined to meet with the larger group on a Saturday. The extract below is selected as it describes Hector's return to an activity that has played a huge part in his life and illustrates the mediating role of all enviroing conditions. This experience plays a significant part in the unfolding narrative presented in the next chapter.

Back in business

I plan to accompany Hector to the golf club and telephone on a beautiful Saturday morning to check the arrangements. He answers and tells me *'we're back in business.'* He advises me when to come to his house so that we can get a lift from Bill, who is married to Gina's cousin. When I arrive, Hector sees me coming through the gate and comes to the door. He is outlandishly dressed in grey loafers, smart trousers, boldly checked shirt, V-neck sweater with a flamboyant golfer motif and a mustard linen-look jacket. I say that he is looking very dapper and he holds out the bottom of his jacket in mock fashion model pose. Bill arrives shortly afterwards and Hector makes the introductions. Before setting off, Hector sifts through a vast assortment of keys in a box near the door. His son Chris is working on his bike and tells him that he won't need them as he'll be there all afternoon. When Hector gets to Bill's car he tries to open the door, but it is still locked. He tries again just as Bill is pressing the electronic key. The process is repeated a couple more times and eventually completed successfully. As we are driving off Bill says *'belt up my good sir'* and Hector responds *'oh, right oh, I'm still trying to get used to these new, fangled things'*.

The last of the Mohicans

Once on our way Hector visibly relaxes, telling me about his extensive involvements with the club, having been a member for fifty years. I remark that the club must have seen some changes in that time and Hector replies *'not half'*. He advises that people used to stay on after a round for a couple of pints, but that changed when they revised the driving alcohol limit. The club had to make many changes to remain viable, *'attracting a new chef and more lady and young members, but the manager still gives us old boys our place'*. For Hector, the oldest playing member, this 'place giving' has taken the form of the recent award of honorary life membership. Hector remarks that his annual membership was up for renewal and *'I'd been in two minds about paying it, because I've hardly been out on the course, but Gina thought I'd regret it come the summer'*. He tells me a little about the men we'll meet and I learn that they served on various committees that helped safeguard the future of the club. I've met Hamish and his son Donald before. Martin is *'a quieter chap'*, whereas Fraser and Duncan *'are blethers, both widowers'*. Hector adds *'we've all lost our closest pals, we're the last of the Mohicans'*.

Good to have the full gang together again

When we arrive, Bill has to use the overflow car park. Hector remarks '*there must be a medal on, but Hamish will have grabbed our table*'. We cross the road and Hector heads round the back way. Three chaps that he '*plays with sometimes*' are teeing off, spot him and wave enthusiastically. Bill points out some new golf buggies, informing me that they cost £25 per round to hire, but Hector has been given free use as part of his membership. He adds '*how to make friends and influence*' and Hector chuckles.

Once inside, we make our way through to the lounge bar. Hector waves across to 'our table', where Hamish and Donald are sitting with another man. Bill asks '*Do you know these scoundrels?*' and I am introduced to Duncan. We are joined shortly by Martin, who gives Hector a manly back pat and says '*good to see you again*'. There is some speculation as to where Fraser has got to and when he eventually arrives there are cries of '*here's the very man*' and they all look delighted to see him, '*to have the full gang together again*'. Several people wave across to 'our table' and one man who has been playing in the medal comes over and tells Hector '*we missed you out there*'.

The expert gallery

The conversation is wide-ranging and includes Scottish and American politics, pensions, education and lots of golf stories. I learn that Hector and Hamish were the only two committee members or '*old stuff shirts*' to oppose the relaxation of the club dress code and the significance of Hector's stylish jacket becomes apparent. The conversation is peppered with commentary on players' shots - *the 'tricky lies', 'shockers', 'terrific crop of young players'* and '*strange club choices*' and they describe themselves as '*the expert gallery*'. The men appear comfortable in each other's company, speaking in unison or taking turns. No one dominates the discussion.

If it's not one thing it's another

Hector takes his turn in the storytelling circle. Typically, he can't remember the name of the chap he was playing with or which course it was, but memory lapses are brushed over and, in this company, he seems relaxed about the slippages. The others also struggle with some of the details. For instance, Martin tells a story about a chap he used to play with who '*had no peripheral vision, good golfer mind*' and how he used to have to stand behind him to tell him where the ball had gone, adding '*his name escapes me*'. Bill quips, '*It's like the old joke about two old men on the golf course. One takes shot and says to the other 'did you see where it went?' to which the other replies 'I did, but I can't remember*'. They all laugh and Fraser says '*true, if it's not one thing, it's another*'.

This one's for your benefit

The stories are very jovial and self-deprecating. At one point however, Hector starts to tell a story about the time he caddied at St. Andrews. As soon as he says '*the Open*', Duncan says to me '*this one's for your benefit*'. Hector goes on to recount that he was up early, sitting outside when an American golfer whose caddy hadn't turned up asked '*do you caddy?*' and he replied '*aye*', adding '*I had a book with the yardage*'. Before Hector gets the chance to continue, he is heckled, leaving no space for boasting: '*Oh, you had a book?*' '*You mean you blagged your way into it!*' '*Where did he come, last?*' '*Did he make the cut?*' Hector admits, '*no*' and they all laugh loudly.

Still got some damage to do

Donald and Hamish are the first to leave and everyone starts to move on. On the way out, Hector points to a panel on the wall plaque listing former champions, saying '*most of these chaps are dead*'. I see that Hector's name appears a couple of times on the panel in question. He looks wistful. When we go outside, Hector has forgotten that we parked across the road and that we came in Bill's car, but Bill makes light of it and Hector does not seem perturbed. When Bill drops us off, he asks Hector '*Same time next week?*' Hector responds '*if I'm still here*' to which Bill replies '*oh, I think you've got some damage to do yet*'.

Interpretation of 'Meeting the Boys at the Golf Club'

The extract begins with an outlandishly attired Hector waiting to make a reappearance at the golf club after an absence of several months. As we set off, family friend Bill overlooks Hector's difficulties getting into the car, more concerned with 'who' Hector is than 'the what' of his condition, helping Hector to relax. Hector's declining health is contributing to a loss of motivation, especially when the weather is bad. Playing golf has been central to Hector's conception of a good life, but he now plays so infrequently that it would be difficult to justify paying the annual membership fee. The award of an honorary lifetime membership opens up the possibility of playing a little longer. Hector can still strike the ball sweetly, but walking the course is challenging. Being granted free use of the golf car enhances the possibility of playing a few holes and perhaps extending this opportunity to his peers.

Ricoeur's (1984) narrative theorising emphasises the pre-narrative quality of ongoing action and the complex temporal nature of experiences as they are lived. The enduring experience of going to the golf club connects Hector to his past, present and imagined future. In conversation, he moves seamlessly from being the oldest playing member at

present, through recollected days, to the renewed possibility of still being able to play in the days to come. The future that Hector imagines is an uncertain one however. He had thought perhaps his playing days were over and while seeing renewed possibilities for continuation, there is an awareness that one outing will be his last.

Hector's advancing years are also impacting upon his social involvement with the club. His closest friends have died and whilst Hector's relationships with former committee members have come to assume greater significance as a result of their respective losses, there is a bitter-sweetness to these connections; a good life is lived with and for others, solicitude underscoring our need for friends (Ricoeur, 1992:192). Ricoeur (1984) illuminates the semantic function of memories, recounted by the men as small stories with dramatic structure, underscoring their emotional significance and poignancy. The history of the club and personal histories are entangled and the scene in the lounge bar is already charged with echoes of what has gone before.

A consciousness of life and its finitude permeates the discussion and a more generative future is alluded to. Many of the men whose names are etched on the trophies and plaques are deceased. Having won competitions and held office, Hector is assured his place in club history. The men also delight in the number of youngsters coming through. Forging connections with, and finding fresh meaning in past events, they recognise that changes to the club constitution that they helped to oversee will ensure the club persists after they have gone. For Hector, a traditionalist, the relaxation of the dress code is regrettable, but he continues to demonstrate his particularity, wearing his bold mustard jacket with pride.

Ricoeur (1992) depicts the field of action as composed of a hierarchy of units of praxis. At the level of practices, games are excellent models, enabling parallels to be drawn between the game of golf and informal group membership. Each practice is comprised of basic actions governed by constituent rules, developed over time. The shared meanings enable evaluative (and subsequently normative) appraisals to be attached to precepts of doing something well and each practice has its own standards of excellence. The group of men that Hector belongs to enjoy a homogeneity of interests and experiences that are the core constituents of their conversations, namely a shared love of golf and the shared experience of men growing older. As a collective, the men are equipped to critique the shots and club choices of those who are playing, constituting '*an expert gallery*'. Their discussion draws on individual as well as shared memories,

but the content of their talk is made meaningful through their experiences as accomplished practitioners of the game of golf, and of life.

The informal group's mode of interaction is similarly governed by its own 'rules', the stories told in accordance within the established norms of this narrative environment (Gubrium and Holstein, 2009). Each man is expected to take a turn, to monitor his own input and, critically, to be '*good company*'. Humour, tales of mishaps on the course or the achievements of others are well received, but blowing one's own trumpet is not. Breaches are subverted through humour; Hector's caddying yarn is instantly identified as '*being told for my benefit*', the subtext being that there is no need to impress the group. Deficits in turn are accepted, brushed over, normalised as part of ageing. Memory loss is treated in the same vein as impediments such as failing eyesight, an inability to walk the course or swing a club - '*if it's not one thing it's another*'.

Ricoeur (1992:184) highlights that friendship exists between those of equal rank, adding that friendship is an activity and thus requires exercise. These men originally held different positions within club committees and have become friends over time. The informal dialogic conventions cooperatively developed now contribute to this sense of equality; they must be upheld. The group has also established an expectation of attendance. When Fraser is late, the men wonder where he is, he is missed. Hector was missed during his absence. If he stops going, the others will miss him too. The men make the effort to attend each week in part because it is mutually beneficial and there is a sense of responsibility to each other, to the group as a whole.

Finally, Ricoeur's (1992) hermeneutics of the self extends beyond a good life, lived with and for others to encompass considerations of 'just institutions' in the social as well as the legal realm. Changes in societal attitudes, demographics and legislation have been reflected in the constitution and daily running of the club, and the habits of members have changed. Of necessity, 'the club' has adapted to appeal to a more diverse membership comprising men and women of all ages, whilst ensuring the older men, '*the expert gallery*', retain their status. Awarding Hector an honorary lifetime membership is consistent with this shift, recognising his unique achievement and placing a value on his ongoing contribution to the social fabric of the club. Within the informal group and within the club, memory loss does not define him, Hector experiences solicitude and equality, enhancing self-esteem and self-respect (Ricoeur, 1992).

Ann and John: Managing Expectations

Each of my meetings with Ann and John takes the form of '*chatting in the small sitting room*'. '*Talking together*' and '*contributing to family life*' are the activities that Ann and John identify as most important to them at this time in life. John is certain that their daily exchanges not only stimulate Ann's memory, but also contribute to the preservation of her remarkable intellectual abilities. For both, looking back on their life together and thinking about the ongoing achievements of the family increases feelings of self-esteem, mutual respect, intimacy and love. The dialogue between Ann and John takes centre stage, although unannotated transcripts could create the impression of adversarial exchanges, quite contrary to the warmth and joviality of my own experience of being with them. The following extract from our third meeting is chosen because it is fairly typical of the discussions in both subject matter and style, touching on several themes that we revisit and develop over the study period.

Unpredictability and happenstance: how does your garden grow?

Looking through the sitting room window, I admire the mature garden surrounding the house, which boasts an untamed beauty, typified by the remarkably early primroses emerging through the cracks in the paving. Ann is first to respond to:

Ann: Yes, it retains a certain loveliness and I'm still surprised by the way things have of finding their own preferred places to grow. I used to spend hours in the garden. I still potter, more a case of pointing out the weeds than anything; very important to people like John who have never really understood what a weed is. My father was very fond of the garden. He was a countryman and then when he was in the army in India he was always longing to get back and to have his garden. So, I grew up believing that a garden was something rather magical and a source of great joy, a paradise - and one that was eventually realised. It was very much his area and later I came to understand the importance of having your own space.

John: For some years now I've been threatening to build Ann a greenhouse and I've got everything for it. I just haven't had the time.

Ann: But then if you did that, instead of being able to go out to play, I'd have to go out to work. (*Jestingly*) There'd be that expectation that I'd grow things.

John: I think that was one thing that Ann was rather disappointed about, that I didn't have much interest in gardening.

Ann: No, I didn't mind at all. In fact, I think I rather preferred it because it was my thing. And besides you were always so good at things, I would not have enjoyed the competition. And I could make my own mistakes without worrying about it. I think one of the nicest things about gardening and growing things, like all living things and life generally, is that you never really know what's going to happen.

Staying with the flow of the conversation, as required by the methodology, I remark that 'never really knowing what's going to happen' is an interesting reflection on life.

Ann: Perhaps that's why I always preferred a country garden, I never liked things that were terribly neat, terribly planned.

John: And when we first came here we used to grow enough potatoes to feed the family over winter. Well, when I say we, the boys did the bulk of the digging.

Ann: Yes, they remember and they accuse us of slave labour (laughter).

John: Our daughter had a pony that provided manure as well as keeping the grass down. And we used to have midnight games of hide-and-seek in the garden and things like that.

Ann: A reward for all the heavy spade work - give a boy a torch (more laughter).

Talk of their children moves the conversation on to the subject of parenting. John describes Ann as '*a truly wonderful mother*' and extolls the benefits of her University education in terms of what this meant she was able to give to their children. I notice that Ann looks contemplative and when I ask rather clumsily if she feels her time at University prepared her for her 'role' as a mother, she responds diplomatically:

Ann: That's a difficult one in that on the whole I've never really thought of it as being a role; I was there and they were there. I have thought about it in the past and realised how much of it related to how my mother was. She wasn't a well-educated woman, but very astute and I always felt that her attitude was to give everyone a chance to have their say or make their feelings known. It's very difficult when you try to analyse why you do things or where the ideas have come from, they are just there. I didn't have a plan. I didn't ever think about the sort of mother I wanted to be. It just happened. An awful lot of things in life do.

The changing nature of relationships within the family: seeing and not seeing

As we chat, Ann hears a knock a rather faint knock at the door that neither John nor I detect. A package is expected for one of their fourteen grandchildren, a budding tennis player who *'requires rather a lot of equipment'*. Ann has been listening out as the doorbell has been out of commission for some time. John congratulates her and goes to take receipt of the delivery. This opens up a discussion about the changing nature of contributions within the family.

John: This is something we can do, practically. One aspect of getting older is managing expectations, both our expectations of the family and their expectations of us. More and more we are going to have to learn to become passengers as they do more things for us, but there is a unity within the family that we can and should contribute to. Our children have their own lives, they are on their way, so we concentrate now on our grandchildren and try to help them.

John gets up and takes down a framed copy of a poem written by the budding tennis player. It sets out the rather different contributions that each grandparent makes:

Grandpa *'sets hard maths questions 'cos he thinks they're fun and takes five sentences where others use one'*, whereas Gran *'comes out to be my goalie when she'd much rather rest and sees the best in me when I'm not at my best'*. Together *'they shiver on touchlines but really don't mind, they're my gran and grandad and they're one of a kind'*.

I think it captures their distinctive, complementary qualities and coming together through their shared commitment to the family beautifully and say so.

Ann: Yes, it's a rather lovely insight, although the opportunity - to be able to do things - seems to be less and less.

Me: Opportunity? To be able to do things (*struck by the 'goalie' reference*) ~ is that physically?

Ann: Yes... and also not being able to do things because - well, they are not around as much. Before they were always around.

I ask how frequently they see their grandchildren and John explains that they see some less often than others through a combination of parental divorce, living further afield, or simply growing up, with the older ones now working or studying across the country. Ann is such an engaging conversationalist that I 'forget' about her memory loss. My question is too direct, an unintentional memory test, but Ann responds masterfully,

'there can be quite a long gap between seeing them, but the memory of when you saw them last is so strong, you forget how long it is'.

John continues, admitting *'when we are not going to see them for some time, well there's a disappointment, so we have to cope with that in various ways'*. He explains both the difficulties and importance of getting everyone together, adding that he and Ann organise extended family gatherings to mark special occasions. He hands me a beautiful photo album commemorating his 80th birthday party, which brought together his brothers and sister and their children and grandchildren. John indicates that they will be doing something on a smaller scale shortly to mark his 81st birthday, but his brothers are keen for a repeat and he is trying to arrange this to celebrate Ann's forthcoming 80th. Ann's actual birthday falls in the winter, but John has *'had the brilliant idea of having a sort of Queen's official birthday the following year'* once the weather is better. When I ask Ann what she thinks about John's brilliant idea she agrees that it will be lovely to see everyone again, but *'can't quite understand how it came to pass that I will be eighty years old'*.

The nature of inquiry and the significance of the final years

After talking about the various things that the grandchildren do that add to the difficulties of getting such a large number of people together, John reflects *'it strikes me that we ask what they are doing and what they want to do, but there is very little by way of inquiry that comes back the other way'* before catching Ann's expression:

John: 'You're looking quizzical love'

Ann: Yes, I'm just thinking about that. It's not something that surprises me or that I've even really thought about.

Still looking quizzical, she continues:

Ann: I suppose it's a case of curiosity. We're curious about them, but they are not the least bit curious about us because we're just gran and grandad and they know all about us, as far as they're concerned. We've always been there.

John heads across the room to a desk area covered in papers and instantly retrieves the latest version of 'how we first met', suggesting that he suspects they will be interested one day and so he's set it all down for them, to which Ann ripostes jestingly *'whether they want it or not'*.

John: Quite; but we often talk about how we wish we'd spoken more to our parents. They were marvellous people. I would love to have spoken more to Ann's father about his time in the army.

Ann: Yes, and I can think back to times with our mothers too, things we should have asked. We didn't think of it at the time. I think there were just so many other things to think about.

John: I think this is my point love, that the significance of things often only becomes apparent with advancing years... Now, looking back, I can see so much of that magical year at University when we had no responsibilities to anyone but ourselves is reflected in the way that we are now. Later, what with the honeymoon baby and having five children, well, we did a lot as a family, but our ability to do things as a pair was very much curtailed, so we tended to do things separately for a while, but there was always a wish to be doing things together. Well, on my part I have to say.

Ann: Oh yes, and if the opportunity ever arose we seized upon it, didn't we? We'd go and do things together or go off somewhere together. Now, we are always together, there's no escape (Laughs).

John: And the glory of it is, is that love we felt for each other back then has lasted until now and the love that I feel for Ann still grows.

Interpretation of 'Managing Expectations'

The above extract documents the place of conversation in Ann and John's everyday life and illustrates the blend of fresh topics, personal and shared memories that characterises their talk. There is a continuity to this practice, as Ann and John have delighted in discussing and debating things since they first met, extending the temporal depth of their shared memories and the possibilities for the stories to be co-constructed, bringing together their different ideas. Taking turns when narrating common experiences, they fall into a pattern, John supplying the bulk of the detail, '*taking five sentences where others use one*', Ann following up with the witty one-liner.

Ann and John are seasoned reflectors and engage in personal and joint meaning-making processes. Ann, a former teacher, demonstrates a strong affinity with the naturalism of John Dewey, highlighting the inherent uncertainty in life, the place of happenstance and the nature of inquiry. John identifies strongly with the notion that the significance of past happenings often only later becomes apparent and recognises the benefits of

'reading our lives' (Randall and McKim, 2008), attributing considerable value to the different perspective acquired with advancing years.

The complex temporal nature of human existence is not only manifest in their talk, but the connections between past, present and future are often articulated explicitly. The extract begins with the enduring experience of looking out of the window and admiring the garden that Ann has cultivated over the last fifty years, a scene redolent with scents, sounds and images of the past. Ann moves from the retained loveliness of the garden in the present and its ongoing source of wonderment, through times she previously spent in this garden and back to her current limited efforts, making light-hearted reference to John's persistent inability to differentiate weeds from plants. Ann's personal time travel continues to a temporal destination when there was no such view, when a garden was something imaginary and magical, reconnecting Ann with her father and her formative years growing up in India. She goes further, explaining what the garden meant to her father and identifying with his meaning, namely the importance of having your own space, a place to experiment and see what happens, a place to make mistakes unobserved, without worrying.

John, keen to rekindle Ann's interest in gardening, sees and suggests future possibilities, but the proposed greenhouse is a contrived, functional space, too constraining for Ann and charged with expectations of work rather than play. Ann resists these expectations. The garden has served many different 'functions' in the past, providing potatoes for the family, a pasture for a pony and space for children to play, but these functions are no longer required, discontinued. Meanings however are not confined to functions and their outcomes, but should also be understood as flowing from the aesthetic, imaginative, creative and emotional modes of interaction with the world (Ricoeur, 1984). With little coaxing, the memories and meanings the garden holds for Ann find their way through, like the unexpected winter primroses, out into the light. For Ann, 'gardening' may have been reduced to pointing out the odd weed, but the 'garden' is an unbroken source of aesthetic delight; it continues to surprise and holds future possibilities, *'like all living things'*.

The parallels that Ann draws between nurturing a country garden and life itself persist throughout the discussion, particularly in her remarks about motherhood and the limitations of rational planning. Instead, she emphasises the influence of her own mother's cherishing ways, which were not learned from a book. It is also evident in her

conversation with John about the evolving nature of relationships and the management of expectations within the family in the here-and-now and going forward; a narrative in the making (Ricoeur, 1984). Both functions of narrative, namely ordering and the creation of spaces for imagining future possibilities are evident.

Once again, Ricoeur's (1992) expansion of the field of action is instructive, characterised by a two-way movement between different levels of praxis. The notion of mobile and necessarily changeable 'life plans' supports consideration of the vast practical unit of 'family life' and the importance of fluidity. Interdependence is not disputed and there is an acceptance that more help will be needed in future, with Ann and John actively preparing for that time. Alongside this sits the concern that they must continue to be afforded the opportunity to contribute to family life in different ways. Traditionally John has set challenges and offered advice, Ann has looked beyond shortcomings to appreciate good qualities '*seeing the best in me when I'm not at my best*'. With opportunities increasingly limited as the grandchildren grow, thoughts turn to practical and unifying alternatives, from taking in parcels to celebrating life together, replacing fading photographs of extended family with new ones.

An explicitly generative sense of the future is communicated through concern for their grandchildren. John is preparing for a time when he will not be here and questions may be asked by setting his version of events down on paper, Ann by modelling ways of being, letting people find their own preferred places to grow. Both recognise the influence of their parents, extending their temporal horizons into the past. Ricoeur's (1992) higher level of praxis, the narrative unity of a life, also serves as a guiding ideal. The past is revisited and new meanings found, whether in a magical year or snatched moments together, helping them to make sense of their togetherness in the present and sustain them going forward. Reading the past is a shared source of wonderment, much like the garden is for Ann, a midnight game of hide-and-seek by torchlight the reward for the heavy spade work conducted over a lifetime.

Jim and Mary: Fault Lines ~ an Afternoon at the Stroke Club

When I first meet with Jim he is still volunteering each week at a local stroke club that he helped to establish more than a decade ago. Jim tells me that the club is the one thing he looks forward to each week and describes it as his '*anchor*.' He suggests that I accompany him there, checks this out with the members and makes the necessary arrangements with the organiser. It transpires that this is to be Jim's last week 'helping'

at the club due to mounting concerns about the frequency of his falls. Experiencing the ending of this involvement with Jim and Mary proves critical in shaping my understanding of the complexity of their situation and the various relationships at stake. It proves pivotal in the unfolding narrative set out in the next chapter.

This is going to be his last week

I telephone to check that it is still convenient for me to accompany Jim to the stroke club. Mary answers the phone and sounds hesitant, going on to explain that Fiona (one of the organisers) phoned earlier to express concerns about Jim's continued involvement. Mary sounds as though she is struggling to make sense of this development. I learn that *'Jim has had quite a few falls'*, including a very public fall at the golf club and another *'bad fall'* a couple of nights before in the bathroom. She adds *'he's fine and you know what he's like, he's trying to carry on regardless'*, before concluding that *'Fiona said they don't have the numbers to cope with him and because he hasn't had a stroke he's not covered and... Anyway, he's not able to help anymore, so this is going to be his last week.'* Having been reassured that Jim is still expecting me to accompany him, I drive to their house.

We'll see...

On arrival, I see that Jim has a black eye and the top of his head is grazed. I ask him what he's been up to and he replies that he was at a Burns Supper, which was *'smashing'*. Mary says, *'Speaking of smashing, I think Karen's meaning what you've been up to get your black eye. She'll be thinking I've been hitting you with the rolling pin'*, and Jim laughs *'no, no, self-inflicted wounds'*. When we prepare to leave, Mary tells Jim that he'll need to take his stick. He tuts irritably, but takes it. He tells me that he's glad I'm coming along and thinks I'll see why he *'finds it very gratifying'*. Mary reminds him that this is going to be his last week, to which Jim responds defiantly *'maybe, we'll see'*. He walks briskly to the car, gets into the passenger side without any real difficulty, but struggles with the seat belt, which Mary eventually clicks into place.

An extra pair of hands is always welcome

When we arrive at the venue, Jim unclicks his seat belt and gets out of the car. He takes his stick from Mary and starts walking towards the entrance. Mary tries to take his other arm but he jerks it away and lets his hand swing free. As we walk, I learn that Mary usually drops Jim off outside and waits for him in the car park when the club finishes. Fiona however has asked her to accompany Jim into and collect him from the meeting room. Mary sighs after telling me this. Once inside the room Jim takes off his

jacket, putting it and his stick on the back of a chair. Once he is seated 'safely' Mary heads off. Jim says to me *'you'll soon see I am not the only helper'*. In addition to Fiona and her husband Alan (the 'organisers') there are several '*ordinary helpers*' like Graham and Jackie who are first to arrive and Eddie's wife, who is *'just Eddie's helper'*. They are all most welcoming and I'm told *'it's a very informal group'* and today will have a Burns Supper theme. When I offer to help, Jim says *'an extra pair of hands is always welcome'* and Graham explains that they set up a large table in the middle without any chairs round it, as most of the '*members*' use wheelchairs.

Are you going to let this stop me from coming?

While I am helping to arrange the furniture, Jim gets up and starts moving one of the chairs. Fiona spots him, shouts '*Alan*' and nods in Jim's direction. Alan approaches Jim, touching his arm in a mock punch. He pulls up a couple of chairs, sits down and encourages Jim to sit beside him. I hear him tell Jim that he's '*some man*', pointing to his eye, and adding that he *'can't be helping with the chairs and things anymore'*. Jim then asks about Fiona's phone call, saying *'I hope you know me well enough to know I'm not the sort to sue'*. Alan agrees, but states that some of the members are worried about him, and they need to think about them too. Jim then says *'Mary says I've not to come any more. Are you going to let this stop me from coming?'* Alan shakes his head, puts his hand on Jim's shoulder and responds, *'No one is stopping you from coming, but you can't be helping out the way you used to'*. Jim says *'good, that's good - I don't want to stop coming'* and his shoulders rise in relief.

It's difficult not to help when you are used to being a worker

The bus bringing the members arrives and as the helpers make their way to the entrance, Jim heads out to the toilet. A short while later Graham re-enters the room, announcing that *'Jim was trying to push one of the wheelchairs'*. Alan escorts Jim back into the room, holding his arm very tightly and sits him back in his chair. Jim tells me that he had '*forgotten*' adding slowly *'it's difficult not to - help - when you are - used to being - a worker'*. When the meeting kicks off, each of the helpers, with the exception of Jim, has a pre-selected piece of poetry to read. Jim laughs and cheers after each recital, but doesn't contribute to the subsequent discussion. He looks very relaxed and happy just to be there.

At one point, I become aware that Jim is reaching out with his hand, very slowly and uncertainly, towards the lady to his left's arm. She is wearing a black jacket made of a

padded material and the sleeve is lying in folds. Jackie is sitting directly across from Jim and looks unnerved. I touch Jim's arm and ask if he's alright and he replies, *'It's just a coat, it looked like it was floating and I couldn't make out what it was'*. The afternoon concludes with a quiz, which Jim struggles with. While the prizes are being handed out to the winners, Jim calls Mary using the speed dial on his phone to tell her they are finishing up. He has to shout over the announcements and applause, drawing one or two stern looks from his fellow helpers.

It would be better all-round if he didn't come back

While the clearing up is going on, Jim makes his way to the toilet again and Fiona goes after him saying over her shoulder *'He can't be walking about on his own'* and takes his arm. Alan follows her and takes over. When Fiona returns she tells me that *'nobody wants to upset Jim or stop him from coming'*, but it is a *'very difficult situation'* for them. She explains that he doesn't qualify as a member as he hasn't had a stroke, but he isn't able to help any more, now needs more help than any of the members, and there are not enough helpers to manage his risk of falling. She adds that the members are worried about him and every week he comes in and he's had another fall, another bruise. It would be *'very upsetting for the members if he had a bad fall during a meeting'*, plus they are not covered for him and every year it gets more difficult to secure funding. Fiona concludes that he could come back if he didn't keep getting up and walking about, or if someone stayed with him, but *'Mary seems to think it would be better all-round if he didn't come back'*.

Changing of the guard

Jim reappears with Alan, who walks him back to his chair at a painfully slow pace and stands over him until Mary comes to take him home. When Mary arrives, there is a brief exchange of pleasantries, but no conversation as to whether this is to be Jim's last week. Jim is stiff and slow getting out of his chair and it takes him several attempts to stand up. He tells me, *'Treacle feet. I'm always worse when I've been sitting. At home, I like to get up and walk about every now and again, but I've had to stay in my seat all afternoon so I've seized up'*. Jim walks with his stick out to the car, more stiffly than before, but still quite briskly and Mary simply walks alongside him. He gets into the car unassisted and promptly falls asleep.

Interpretation of 'Fault Lines'

The above extract illustrates the ways in which everyday action connects to practical and moral dilemmas in a social situation where there are multiple, competing interests

at stake. Mimetic theory affords the following interpretation. *Mimesis1* concerns those aspects of action that have a pre-narrative quality and is the means by which acting and suffering rise to meaning at a pre-reflective level within a particular situation. Some moments and events possess greater narrativity than others, they are 'lit up with the qualities we take to belong to finely wrought narrative' (Mattingly 2000:189). The scene that unfolds possesses many of the attributes of a Greek tragedy.

The extract begins with Mary struggling to make sense of the latest happenings, to bring concordance from discordance. The pre-narrative quality of action does not mean that the plot is always clear. It falls to Mary to explain to Jim why he can no longer help out at the stroke club. Yet she herself cannot grasp how the club that Jim was instrumental in establishing, where he has volunteered for many years and which caters for people with diverse physical and cognitive impairments, cannot accommodate him in his hour of need – '*on top of everything else*'. She feels that Jim's input is not being recognised. For Mary, this event takes its meaning, not from itself as a single occurrence, but from the contribution it makes to the narrative as a whole; ending Jim's involvement with the club means pulling up his anchor.

In addition to ordering and giving meaning to events, the mediating operation of emplotment can create the space for considering other possibilities for action. The plot of this unfolding story is not fixed and Jim envisages alternatives. Ricoeur (1992) stresses the importance of the 'ending' in any given narrative, and acknowledges that in real life we are more like the characters in the story than the narrator, as we are unable to see ahead to consequences and unable to read the eventual meaning that actions and experiences will acquire. However, he also highlights that we have experience, however incomplete, of what is meant by ending a course of action. With Jim's words '*we'll see*', the ending of this particular 'slice of life' (Ricoeur, 1992:162) is suspended, paving the way for him to try to convert his act of imagination into an act of will. The action that follows is thus charged with the dramatic question '*Is this to be Jim's last time?*' and the knowledge that the different actors have shared histories but different endings in sight.

Ricoeur's (1992) consideration of the relation between narrative and action in terms of a nesting of constitutive levels of praxis is again instructive. The inherently interactive practice of volunteering is comprised of basic actions and configured by constitutive rules that give each action its meaning. Actions can be appraised as appropriate or inappropriate. The notion of practice also assumes capability and competence, which

can be evaluated by others. Jim is no longer deemed competent. In addition, despite the professed '*very informal*' nature of the club, it has its own hierarchy and is bound by constitutions, rules, norms and other symbolic resources, both internally derived and externally shaped. To be a member you must have had a stroke, to be a helper you must be judged capable of helping. Jim does not meet the criteria for either category.

Jim's lack of capability is largely attributable to the increasing fragility of his body. It has become an uncivilised body, an embarrassing body (Elias, 1978) that falls over and will not stay seated, that bruises badly, shouts out during prize giving and reaches out uncertainly during group discussions. Jim has helped at the club for many years and helping has become habitual, unthinking. He forgets that he is no longer permitted to help, but his body remembers how. The past is in his behaviour, habits wear grooves and enforced changes may be difficult to make – '*It's hard not to help when you're used to being a worker*'. Basic actions previously evaluated as helpful are now judged to be risky or disruptive. For Ricoeur, (1992) action takes its meaning - 'as helping', as 'work' – only from others, underscoring 'the extraordinary precariousness of the relation between work and its author, the mediation of the other being so thoroughly constitutive of its meaning' [Ricoeur, 1992:156].

At the next level of praxis, Jim's 'life plans' have undergone major revisions since the onset of his condition. Taking part in the stroke club is the last vestige of an enduring commitment to put something back into the community. It is a legacy, a source of gratification and keeps him grounded. Rather than constituting 'a fluid intermediary zone of exchange between determinate practices and guiding ideals' (Ricoeur, 1992:172), his aspiration to participate has become resistant to change. While Jim refuses Mary's discreet attempts to support him, to continue volunteering he is prepared to submit to a vice-light grip as he is escorted back to his seat at an exaggeratedly slow pace. He tries to remain seated knowing that it will cause him to seize up. The nested levels of basic actions, practices and life plans are however on a collision course and, like a tectonic plate, the fault lines expand each time Jim shifts. Jim's body is the primary source of his perceived vulnerability, but his fatal error is that he has 'misread' the situation – another pair of hands is not always welcome. The club needs a safe pair of hands and Jim now constitutes a risk.

Ricoeur (1992) highlights that situational interpretation requires judgement and we aspire to plausibility in the eyes of others. Jim's efforts to achieve continuity are

perceived by others as implausible, creating discontinuity, upsetting the order of the club that he co-founded to provide its members with a haven from distress. The interpersonal relationships and friendships at play within the situation compound the difficulties. The organisers know *who* Jim is, they recognise his uniqueness, but *what* Jim has become places him on the wrong side of the moral gateway. No one wants to disesteem Jim, no one wants to deliver the message: you have fallen, literally and metaphorically, into the category of 'Other'; do the 'right thing'. The organisers perceive making a dignified exit to be the right thing, Jim clings to the stroke club as the last remnant of a good life; his ethical aim cannot pass through the moral sieve (Ricoeur, 1992). Mary is trying to support Jim to persevere but the avenues of possibility are closing and she too is judged more unfavourably with each successive fall, *'He can't be walking about on his own any more'*. As they leave the club together, Mary does not even try to take Jim's arm, but walks alongside him, matching his own pace.

Chrissie: Sink or Swim / Piccadilly Circus

I struggle to choose a single meeting with Chrissie because each encounter is so different and there is no obvious storyline opening, anchor, turning point or reversal. During school term-time, Chrissie goes swimming every weekday morning and takes part in a twice-weekly aquarobics class. This perhaps appears to be a strong candidate to focus upon and it offers important insights into some of the practical difficulties that age-unfriendly environments can present. However, this focus is too one-dimensional and the meticulous planning that it entails is completely at odds with what I initially perceive as the chaos of Chrissie's private world, where paradoxically, she seems more certain. I therefore recall two contrasting experiences below.

Sink or Swim

I arrive at Chrissie's house around 9:30 a.m. and as she answers the door I spot her swimming bag in the hallway. She has a checklist to make sure she has everything she needs, including £2, £1 and 20p coins for admission, locker and hairdryer respectively, which she takes from the 'swimming jars' that her sons keep topped up for her. Chrissie tells me that, growing up as one of nine children, she was *'really lucky'* to learn to swim:

'My dad never had much money, but he handed over his wages. He wanted us out from under his feet on Saturday mornings and we'd go to the baths for hours. The wee ones got in free, but me and my older brothers always had bus fares and money for a swim. My oldest brother got lessons at school, but the rest of us taught ourselves, it was sink or swim'.

The main road through town is the most direct route to the leisure centre, but Chrissie goes *'the top way'* because it is less busy. The journey takes around five minutes. On the way, I learn that Helen, Chrissie's daughter is struggling to learn to drive. *'She never bothered before because she couldn't have afforded to run a car and never needed one'*. Chrissie has stopped driving Helen to work so that she has more of an incentive, adding, *'My son has told them all they can't keep using me like a taxi. I'm fine just now, but I'll need to stop some time'*.

Chrissie initially looks for a parking space close to the entrance of the leisure centre, which would require tight manoeuvring, before continuing to a less occupied section of the car park. I learn that when she comes alone she parks as close to the door as possible so that she can see the car when she comes out, otherwise she won't remember where she left it and starts to panic. She remarks that she would like a disabled badge, but if she asked, they'd say she's not fit to drive, adding *'but driving and remembering where you park are two different things'*.

I'm not that bad

Before leaving the car, Chrissie opens her purse and puts her season pass and the three coins in her jacket pocket. She tells me she shouldn't need her pass as she told the woman at the desk that she had Alzheimer's *'when it was quiet'*. *'I had to because I was getting flustered unzipping my bag, opening my purse, taking my pass out, putting it back, especially when there was a queue. I said to her 'I come every day, you know I have a pass'".* Having lost her purse a few times, Chrissie is anxious about leaving it at the desk. She keeps hold of it until she has locked the car, hooks her keys onto a keyring attached to the purse and places them in her bag. As we walk she tells me *'I didn't like telling her as there's still not that many people know I have it. I don't want folk knowing cos they start looking for faults and that's the beginning of the end. I'm fine as long as nothing panics me. If I start to panic, I can't think'*. She informs me, *'You'll see her when we go in, with her big sympathetic face. She speaks to me as though I'm not the full shilling. I mean, I'm not that bad'*. When we step inside, sure enough, I see 'the big sympathetic face' behind the desk saying very slowly *'Hello, how are you today'*? She has a self-adhesive pink band for the steam room ready for Chrissie and says *'there you go dear'*.

Strategy deployment

When we go through to the changing area, Chrissie tells me that she always takes a locker as close as to the showers as she can. She points to the lower row of lockers and

says *'People usually go for the top ones, but I always take one in this block, first from the end if I can get it'*. She then removes the wrist band and locker key from the door, saying *'See, the numbers have faded. I can't read them without my glasses. I won't remember my number, but I can remember where my locker is'*. I notice Chrissie touch her ears, I think checking that she has taken her hearing aids out. She has. We each attach the pink wristband, which proves a bit awkward (and a nightmare to remove afterwards).

The class is badged as '50+' but most participants are considerably older. A few people wear inflated armbands around their wrists instead of using the foam weights, Chrissie suggests because *'their arthritis is worse than mine'*. I also overhear a conversation indicating that the instructor sticks to the same programme to make things easier for the oldest participants. Chrissie has told me in advance that without her hearing aids she can't hear the instructions and initially she looked to see what the instructor was doing. However, she soon discovered that it looks different on dry land, advising me that it's better to watch people in the water. When the class starts I look around, but no two people are doing the same thing. I watch the instructor instead and think I'm doing well when Chrissie points out that I need to keep my arms under the water. Ah, it's actually quite hard work.

Plenty more fish

The exercise programme comprises a mix of star jumps, spot running and frog leaps, with the instructor constantly shouting *'Listen to the beat team, try to move to the beat, to the beat team'*. The 'beat' is surprisingly pacey and the programme runs for an hour. Some of 'the team' leave after 40 minutes as the pace picks up, but Chrissie manages to 'keep to the beat' and is really working her arms, which I notice are remarkably toned. When it comes to the 10-minute cool down, Chrissie indicates that she prefers to go for a swim at this point and I follow her to the other end of the pool. She starts doing widths, including *'a couple of the crawl, cos it's better for your arms'*. When I ask about this as we later relax in the Jacuzzi she explains, *'I've always been vain; I can't kept help it. I've never had any problem attracting men, pigs mostly, but that was my talent'*. She adds, *'I still get a few hook ups on PlentyofFish¹⁷'*. Catching my stunned expression, she asks if she's shocked me. Initially I say *'No, just pleasantly surprised'*, but I know how well she can read people and admit *'well, maybe a bit'*. She laughs, telling me that she's

¹⁷ Plentyoffish is an internet dating site

not really looking, but it's nice to see who she could get and promises to show me her profile page later. She quips *'It's alright, I'm in the silver pond, not the naughty pond'* and we both dissolve into hysterics.

Back in the labyrinth of the changing room, I notice several women anxiously trying to locate their lockers, like participants in a macabre version of the 'Crystal Maze', none having adopted Chrissie's winning strategy of using the lower row. When Chrissie advises me to use the middle hairdryer *'cos it runs forever'*, I conclude that she's quite a catch.

Piccadilly Circus

Visiting Chrissie at home during the school holidays offers a marked contrast to the anxiety fuelled trip to the swimming pool. When I knock on the front door, Craig (Chrissie's 'adopted' grandson) answers and asks me excitedly, *'Have you seen the puppies?'* He has a friend with him called Neil. When I go inside I discover that Poppy, Helen's Yorkshire terrier, has had two puppies, one of which is about to be sold. Helen is working and it has fallen to Chrissie to oversee proceedings. Two young girls are sitting in the lounge. I notice some furniture in the corner of the room and Chrissie explains that Helen put an old wardrobe on e-bay and a man who has just moved into an unfurnished flat is coming to take it away later that afternoon. Chrissie says, *'It sounded as though he has nothing, so I've looked out a few bits and pieces for him too'*.

Free to a good home

Chrissie asks the boys to take Poppy for a walk so she isn't there when the girls take her puppy away and they oblige. A photo shoot follows and there are promises to keep in touch via Facebook. The boys come running back in at this point, saying they want to take photos too. Chrissie asks them to hurry as they need to take Poppy away before the girls leave. As soon as the girls depart, Chrissie uploads the photos to her Facebook page, showing me a photo of her dog, Stanley, who I learn has *'gone free to a good home'*. Chrissie asks me to follow her upstairs, where she shows me a shredded carpet outside her bedroom door. Stanley had been scratching at her door all night, but she hadn't heard him because she didn't have her hearing aids in. Eventually she got up and discovered that she had left the patio doors unlocked and they had blown open. Chrissie's unsure if Stanley was frightened or trying to warn her, but concludes *'I'm too old to be looking after him'*. She continues, *'I grew up leaving the doors unlocked because*

we didn't have anything worth nicking, but I've already had a couple of break-ins, so my son's been coming around at night to make sure they're locked - for the insurance'.

It's like Piccadilly Circus

At that point Craig comes back in through the offending patio doors with Neil and Bethany, Neil's twin sister. Bethany has the longest hair I've ever seen. Poppy is not with them and when Chrissie asks where she is, Craig says '*at Natalie's*'. No further explanation is required. They go back out and Chrissie tells me that she's very fond of Bethany, explaining that her classmate had leukaemia and she's going to donate her hair to make children's wigs. I chat with Chrissie as she makes tea in the kitchen. As we move back to the lounge a woman comes through the patio doors with Poppy in tow and gives Chrissie a kiss. I deduce that this must be Natalie, one of Chrissie's grand-daughters. She is looking for Stephanie (her daughter) who had been at Chrissie's house earlier. Chrissie says she can't remember where Stephanie said she was going, but thinks Craig will know. Natalie does not seem too concerned where Stephanie is, or who I am. She heads back out without Poppy. Chrissie comments, '*It's always like this, folk in and out all the time. It's like Piccadilly Circus, but that's the way I like it*'. Right on cue, Craig comes through the much-used patio doors and asks if they can go and get lollies. Chrissie replies '*of course*'. She asks him if he knows where Stephanie is, but he says '*no*' and heads out again. As he leaves, Helen phones to ask how Poppy is.

In safe hands

When Chrissie comes off the phone she tells me how lucky she is to have a daughter. She adds that it looks as though her neighbour, Jessie, will not be coming home from hospital following her recent fall and Jessie's sons are looking for a care home. Elsie, another neighbour is really upset about it. I'm told that Elsie's son is good to her, but he's seventy. Elsie's grandson is a lovely man too and comes to see Elsie every night on his way home from work, but neither of them would think about taking Elsie to see Jessie and Elsie would never ask; '*Men don't think that way*'. Elsie has carers and her son makes sure she has her meals, '*all the essentials, but no wee treats*'. Chrissie takes Elsie a cake every day, '*something fresh, over the counter and we have a good blether*'. While there she often gives the place a quick run over with her Hoover, '*because Elsie's Hoover is done. It's a museum piece. She stresses again, 'Men don't think about that*'.

Chrissie continues this account by telling me that last night she popped in with a couple of cartons of soup and Elsie asked her to put one in the freezer; '*Now I don't know when*

that freezer was last defrosted. Last century. There's stuff in there her son must have put in recently, nice stuff mind, but he wouldn't think to defrost it. I'm not saying he wouldn't do it, just he wouldn't think about it. I've offered to do it tonight and Helen will help 'cos it'll be a job and a half, but Helen would never let it get to that state'. Chrissie emphasises that her own sons are very good to her. James always goes with her to her appointments, *'He knows how to talk to doctors'.* And Frank got her banking sorted *'cos he's on top of all that stuff. But when it comes to the niceties, that's when you need a daughter'.* The conversation is interrupted as the remaining pup makes an appearance and poops all over the carpet. Chrissie, unfazed, deals with it efficiently.

Later, as I am saying cheerio at the front door, an old van pulls up outside the house and a painfully thin and what I perceive to be troubled-looking man steps out. Chrissie remarks, *'That'll be the guy for the wardrobe'* and waves to him warmly. At that moment Craig, Neil and Bethany burst through the patio doors and Chrissie says *'Here's my boy'* as Craig comes to see what is going on and puts his arms around Chrissie's waist. I conclude that she is in safe hands.

Interpretation of 'Sink or Swim / Piccadilly Circus'

In the first encounter, drawing upon mimetic theory, the 'swimming jars' full of coins connect Chrissie to childhood memories of having enough money to go by bus to the public baths with her large family of brothers and sisters. She considers herself fortunate and imagines that things could have been different. Further, she is 'still lucky' in having sons who keep the jars topped up, essential ingredients in a carefully coordinated plan that enables her to continue swimming into the future. Chrissie's imagined possibilities also include a time when she will not be able to drive, but she and her family are preparing for that. They are acting in concert; her sons are alerting younger family members to the demands made of Chrissie and her daughter is learning to drive, having previously had neither the need nor the means to do so. Despite these apparent hardships, through the guiding ideal of the narrative unity of a life, Chrissie is able to frame her health conditions and the changes they may bring within what she perceives to be a good and lucky life.

Chrissie would like a disabled badge and although clear that being able to drive and remembering where you park are unrelated, she won't apply as she feels this would be misrecognised as a sign of unfitness. Chrissie's concern with being identified as incapable extends to face-to-face encounters in public spaces and her fear of people

finding fault is tainting the pleasure of swimming. Being with Chrissie illuminates the steps taken to negotiate the situation, including telling the woman at the desk about her condition. While this has the desired effect of no longer needing to produce her season pass, it comes at the price of being spoken to as if she is 'not the full shilling'. Here cultural assumptions about dementia take priority over Chrissie's particularities; she's 'not that bad'. Once inside, the practice of swimming presents no difficulties to Chrissie, but the physical environment constitutes a direct threat to dignity and self-esteem. Ostensibly hosting a class for older people, embodied needs are neglected and participation requires the successful completion of an obstacle course before entering the water.

Spending time with Chrissie, I come to more fully appreciate the importance of attending to the 'non-substitutability' of persons in considerations of inter-subjectivity. Unlike Chrissie, I was taken to swimming lessons and did not consider this a privilege; I was never left to sink or swim. Our worlds are very different, as highlighted by our amusing exchange about continued fishing expeditions in the silver pond. These differences become more apparent when I enter Chrissie's private world, where her anxieties evaporate and I find myself on shaky ground. I become aware of our different perceptions of risk and Chrissie's family's more 'forgiving' attitude, such as towards her 'failing' to lock doors, to invite 'strangers' into her home, or to 'remember' where her great grand-daughter has gone. Moreover, while 'routine' is often privileged for people with dementia, what I initially perceive as chaos Chrissie regards as standard. She likes living in Piccadilly Circus and doesn't want the surprises to stop.

Chrissie is not only able to contextualise her Alzheimer's diagnosis within a narrative unity, but the aim of living a good life with and for others also persists. Chrissie and her family are part of a network that extends into their local communities. There is an openness to complexity and interdependence indicative of a broader understanding of citizenship (Fisher, 2008). This openness to others causes me to engage with the concept of 'corporeal generosity' (Diprose, 2002), whereby people make a gift of themselves. This extends quite literally to Chrissie's appreciation of Bethany making a gift of her hair. Chrissie's particular contributions are recognised and sustained by the social group to which she is closely affiliated, enhancing her self-esteem.

Elsie's situation also causes Chrissie to 'refigure' (Ricoeur, 1984) her own life and how different her life might have been 'if' she had not had a daughter. In the future

imaginary, should Chrissie's abilities deteriorate, her house will be hoovered, her freezer defrosted, her daughter and grand-daughters will take care of the niceties. There are strong gendered assumptions within this account; Chrissie would not expect a man to engage in treating her, hoovering or defrosting fridges (activities John, Tommy and Hector routinely undertake). The positive sense of self Chrissie gains through caring activities could be attributed to working-class women's reliance on femininity in the absence of other opportunities, particularly given her continued concern with appearance (Skeggs, 1997). Yet it may also be easier to accept care from others, when the time comes, in a local culture where care is valued (Barnes, 2012). Such understandings could easily be undermined by an absence of recognition of Chrissie's particular enactment of citizenship in the wider public sphere, where contractual relationships and biomedical assumptions dominate.

Reflections and Way Forward

The study participants respectively prioritised solo undertakings, activities enacted with friends, as a couple, in an organised group setting, and a blend of individual leisure and informal 'family' activities. The different priorities in themselves offer insights into the diverse lifestyles of the participants, the things they value, their possibilities for continued participation in and contribution to everyday life and the extent to which this depends on others. The differences also shape my level of participation in the activities and in the co-production of meanings. The selected encounters, albeit in different ways, establish narrative meaning-making processes within the flow of actions.

In each case, temporal considerations are key. The importance of attending closely to biography in the experiences of people living with dementia is not new; it underpins Kitwood's (1990; 1997) philosophy. However, as the above accounts illustrate, in the continuity of time, situated actions often connect not only with past experiences, but also extend into imagined futures. Each person or couple's situation is fluid and embedded with welcome and unwelcome possibilities. Each enactment of an everyday activity alludes to ongoing challenges and contingencies and reveals how everyday activities connect to moral dilemmas. It is this aspect of narrative, as an interpretive possibility, that yields a view of human narrative as being constantly in flux rather than a mere ordering of past events.

Each account introduces possible storylines. For Tommy, it appears to be just a question of time until the medical profession finds something else wrong with him and his activities are further curtailed, while Grace is preparing for a time when she takes care of Tommy. Hector wonders if there is still enough time to do some more damage and contemplates his own finitude. Ann and John's account underscores the importance of their relationship standing the test of time as they face old age together, and their thoughts also turn to a more generative future, contingent upon their family's busy lives. Jim is trying to buy time, making compromises to continue with a valued activity for a little longer, while Mary is wondering how Jim's investments over time seem to count for so little in the present. Chrissie in a sense is defying time, entertaining the possibility of dipping once more into the silver pond, the fullness of her daily life ensuring future decline is but a footnote in a good and lucky life.

Ricoeur's (1984) narrative theorising indicates that the plot constantly undergoes change, as new information is accrued, new events take place or previous understandings are altered. Having considered how meanings and connections were made within a specific acting situation for each person or couple, the next chapter contextualises and expands upon these experiences, looking at how the narratives unfolded over the course of the study. It also considers the implications for identity configuration and social recognition of their achievements.

Chapter Eight

Fallen Fruits: Five Emplotted Narratives of Everyday Life

Overview

The previous chapter engaged with situated action and meaning-making processes in the everyday lives of the participants, drawing upon a specific scenario for each. In this chapter, I consider how the participants variously negotiate the obstacles, dilemmas and opportunities of everyday life over the course of study period. I present the fruits of the analysis, using the process described in Chapter Five, in the form of five emplotted narratives. The narratives emanate from the real-time enactments of events, accounts of imagined futures, together with small stories (Bamburg, 2004) of past events told by the participants in the midst of doing everyday activities on the Narrative Inquiry landscape. Each narrative was configured upon conclusion of my time in the field and is thus detached from its life source, the ingredients selected by me from a bounty of fallen fruits. The narratives and the lives of the participants in contrast continued to unfold.

The configured narratives are my interpretation of how various events and happenings deemed significant by participants connect, taking their meanings from their respective contributions to the whole. I also ask what part 'dementia' does or does not play within the different configurations and consider how 'memory loss' or 'dementia' is incorporated into the participants' unfolding narratives and identities. In each case, I identify an overall plot to represent various processes of transformation related to a development in the person or couple's life. Meanings shift and assume new dimensions as changes and unpredictability regarding both bodily ageing and being good enough citizens are negotiated, integrating past, present and implied future. The narrative analyses illustrate how the study participants variously communicated their uncertainty regarding being able to continue to participate in and contribute to society in ways that they find meaningful, and are socially valued. They also illustrate the extent to which participation in everyday activities in local cultures opens or forecloses possibilities for being themselves, as unique and particular persons, rather than being defined by dementia. As such, the narratives represent ongoing struggles for recognition.

Tommy and Grace: Deciding what to do with the Garden

The narrative below expands upon the events and meanings identified through '*A Walk in the Snow*', as set out in the previous chapter. Keeping on top of the garden is part of everyday life in the local culture in which Tommy and Grace live. It speaks to their enduring commitment to being good citizens by participating in and contributing to society, which includes being responsible neighbours. The garden however is a source of ambiguity, associated with the progression of Tommy's condition and Grace's chronic back problems, which together constitute a threat to keeping on top of it. Something has to be done. In emplotting the narrative, I use '*deciding what to do with the garden*' as a structuring device.

During my first meeting with Tommy, he stuns me with tales of his impoverished childhood. As we walk the snowy streets surrounding his home, I come to appreciate the extent of the stigma surrounding his illegitimacy. He recounts various efforts to make himself '*useful*'. Tommy tells me that he had to earn his keep from a young age, delivering milk, mucking out stables, straightening nails for the local undertaker and later working as a groomsman, before eventually persuading a large firm to take him on as an apprentice plasterer. His employment was almost short-lived when they discovered Tommy was left handed, but he'd pleaded for one week to prove himself and found the means to work with the tools. He adds, '*I had to*'. As our walk continues, I learn that a fence has come down in Tommy's back garden due to the weight of the snow and he confidently tells me he'll fix it later. He attaches great importance to being '*a handy man*', advising that he '*keeps on top of things*'. This is followed by a statement that peppers our conversations throughout the study, '*You can't be looking like an old fool*'.

When we get back to the house, Tommy goes to inspect the damaged fence as I chat to Grace who looks on from the kitchen. She tells me, '*A few people have said 'have you not been to the "D café" yet, oh you should go', but I'm not sure. The theatre visits are one thing, but the café? Maybe it's for the future*'. She informs me that they already know quite a few people who are '*further down the road*' and a couple '*at the end stage*' and she is keen to protect Tommy from '*any more of that*' for as long as possible.

Tommy has repaired the garden fence by the time we next meet. We catch the bus into town as he has a few errands to run, including dropping off some bags at the charity shop. Grace's back has been troubling her, she's exhausted and plans to have a nap. However, the neighbourhood 'Sheriff' lives up to his name by pounding on the door to

report that he has just seen Tommy getting on the bus with an unknown woman with two carrier bags containing electrical goods. Was Grace aware of this? She invites him in for a cup of tea.

In town, Tommy chats and jokes with staff everywhere we go, creating queues but otherwise working his way through his to-do list admirably. We stop off in a new Italian café before returning home, where Tommy impresses me with his knowledge of history, an interest that didn't originate in school: *'They couldn't teach me anything to be truthful. I never could write very well, so I got moved in with the useless lot. Twelve of us got put together to keep us in order'*. When I ask if he needed to be kept in order he says *'I suppose I did'*. I learn that Tommy grew up with up with his grandmother in *'a house full of women.'* All the men were at war, apart from the old farmers and they taught him *'all the wrong stuff, like how to draw naked women. Used to say 'good lad' and laugh'*. He recounts an early experience when his teacher asked him to draw a picture and he reproduced the only thing he knew how. He continues *'I showed it to her and she asks 'what's this'? I said 'a naked lady, Miss', and she says 'come with me''*. Tommy was taken to the headmaster, thinking he'd say *'good lad'*, but instead was told *'roll back your sleeve and hold out your hand'*. Tommy illustrates, *'and from here to here, I got the strap. Twice. He concludes 'I never learned anything at school. I had a right bad stutter an' all'.*

Tommy suggests an extended walk in the woods when I next catch up with him, explaining *'I'm needing to burn the fat off'*. I say *'you're as fit as a fiddle, Tommy,'* but he replies *'I was back at that place for this thing I've got and the nurse says I've put on two pounds. That was all they found, this time, but she told me to burn some of the fat off'*. He goes on, *'I tell you, I feel like a sixteen-year old now that I'm back on the fives'*. Initially I think he means five-a-day, but when I say *'fruit and veg'*, Tommy exclaims *'my, you're awfy daft, no my tablets, for this thing, in my brain. S'no for fixing it mind, just slows it down'*. Of course, Aricept. I am *'awf'y daft'*! Tommy continues *'they'd put me on the tens (10mg dose) but I couldnae stand it. It says on the packet what you can get - cramps, not sleeping and needing to be near a damn toilet all the time, so it's not just me that couldnae cope'*.

We return to the house and while chatting, Grace asks if Tommy told me about a recent bus trip into town. I learn that Tommy had been forced to run home to the toilet, didn't make it and had to change while Grace waited at the bus stop. They got home after being out all afternoon to discover Tommy had left the door wide open. Tommy says,

'Well, I don't think those tablets are helping' to which Grace replies *'They were never going to make it better or stop it, only slow it down, but now you've halved the dose'*. Tommy retorts, *'Aye and I feel much better since I went back on the fives'*. Grace sighs, *'at the moment, but it's only half the dose'*.

Tommy's 'going back on the fives' coincides with Grace's decision to increase their involvement with the Alzheimer Society. She visits the "D café" on her own to check things out, concluding that it might be okay. They start going to the cafe and then Alzheimer Society meetings, some proving more useful than others. Grace advises that some people questioned having separate discussions for *'carers'* and *'people with dementia'*, so they're thinking of changing the format. She also starts to think ahead, which includes exploring options for replacing the lawn in the back garden, but Tommy isn't keen.

When we next meet up, Tommy is working in the back garden when I arrive. I remark that the front garden is looking very tidy and Grace says *'it him took all morning, every dog in the neighbourhood was across to see him'* and shakes her head light-heartedly. She adds, *'we're getting the back done'* and Tommy grumbles, *'The Ayatollah has spoken'*. Grace continues undeterred, *'We've been trying to decide whether to get slabs or artificial grass'*, she looks at Tommy who is raking some leaves then concludes *'but we're no further forward'*. Tommy tuts and Grace explains that when he isn't able to do the grass, she won't be able to either. Tommy volunteers *'It's not difficult to use a lawn mower, I can teach you'*, but Grace responds, *'I'm not starting with a lawnmower now. You know I can't even use the Hoover'*. She later divulges that she now has to ask Tommy to Hoover and although he does it without complaining, he has stopped noticing things. She has to point them out. He used to notice things, notice how she was and she misses that.

I accompany Tommy on his daily constitutional, during which he expresses concerns about the cost of doing the garden. It seems Grace had her heart set on new settees, but the garden would have to be instead. He thinks they should go for slabs, then he could pave it himself. I remark that slabs must be really heavy and he tells me, *'The average weight is 70lbs, but you don't lift them, you walk them into place. It's easy if you know how'*. He insists again that he feels like a sixteen-year old.

When we get back to the house, we all have a cup of tea together. Grace is reading a book written by a younger woman with dementia, which is *'interesting, but her issues*

are very different'. Tommy and Grace have also been back to the Alzheimer Society. *'The last meeting was, well it was all about our rights*. Grace glances across at Tommy, adding *'the day to day stuff is useful though*'. Tommy agrees, *'Aye, it's amazing, you wouldnae know who had it and who's the carer*'.

Towards the end of the study, I visit Roslyn Chapel with Tommy to share in his love of history. Grace isn't feeling up to it, informing me there have been *'a few more mix-ups*'. Tommy alludes to this too as we walk down the path, saying he's *'been back in the bad books again*' and that Grace is becoming his *'minder*', adding *'dare say I'm lucky*'. Inside, when the chap at the desk asks Tommy if he's likely to be back, Tommy surprises me by saying, *'Well son, I've got Alzheimer's, so likely I'll no remember what I've seen. Dare say I could come back a few times*'.

There are a few more surprises in store. I read out the description of a carving depicting the acts of mercy and when I come to 'helping the needy' Tommy quips *'It cannae be that Osborne fellow*'. He reveals that, despite saying he *'cannae stand the man*', he's been a lifelong Conservative voter, having been instructed to do so as a youngster by a local Tory MP and landowner. *'Right clever man. Said we had to or we'd be out of a job. You did as you were told*'. When I ask why he still votes for them, he answers, *'Habit, I suppose*'. During the visit Tommy refers to 'Alzheimer's' several times and there is no suggestion that he'd be *'none the wiser*'. Instead, I learn that on a recent trip to the dentist he realised he'd forgotten how to write his signature; *'It hit me hard - this is what it's going to be like*'. He also breaks my heart describing his helplessness upon witnessing Grace's distress when a character with dementia in her favourite soap no longer recognised his wife.

During our wrap-up meeting, I learn that Tommy and Grace plumped for the more expensive artificial lawn. Tommy says he's *'relieved, truth be told*', admitting to falling over while working in the front garden when his *'feet stopped working*'. Grace adds that Tommy had been sitting out in the garden and asked her to come and join him. She continues, *'When I said I had too much to do, he said 'no, please, just sit here with me, let's enjoy it while the sun shines*'. He would have never have said anything like that before'.

Interpretation of 'deciding what to do with the garden'

I come to understand the meanings Tommy attaches to 'keeping on top of the garden' early in the study. The garden is bound up with anxiety about relinquishing his status as a 'handy man' and becoming a burden to Grace. These anxieties are nestled within a

deeper concern about making himself useful more broadly, something instilled as a young boy and reinforced through a protestant work ethic and the rhetoric of active ageing. His reasoning for preferring slabs to the artificial lawn is tied up with being productive and providing for Grace; if he could lay the slabs himself, perhaps Grace could still have the new settees she had set her heart on. 'Keeping on top of' is also consistent with Tommy's desire to maintain things and not think too far ahead.

'Deciding what to do with the garden' holds strong meanings for Grace. When I first meet Grace, I am struck by the busyness of her life as an active church member, her organisational skills, desire to embrace fresh opportunities and commitment to mutual decision making. As a caring wife, deciding what to with the garden lends a practical focus to her need to prepare holistically for 'the big test ahead'. It is emblematic of the daily dilemmas she experiences between protecting Tommy from what lies 'further down the road', needing to prepare for that point in 'the journey', and her commitment to making decisions jointly with Tommy 'while he still can'. This includes decisions Tommy doesn't want to make and that bring an unwanted future and equally unwelcome echoes of Tommy's past into the present.

'Deciding what to do with the garden', like many facets of ordinary life, is accompanied by frustrations and misunderstandings, requiring negotiation and compromise. It is one of many rivers to cross. Once the decision is reached jointly, there is a shared relief and also a new sense of possibility; having relinquished his identity as 'a handy man', the garden is transformed into a place where Tommy might sit quietly and enjoy spending time with Grace, at least for a while. Grace initially resists this as 'just sitting' is incompatible with her ethos of 'keeping busy'. Tommy however persuades her to stop and enjoy some precious moments together 'while the sun shines'. In the dialectic of sameness and selfhood, roles shift, some are surrendered and Tommy and Grace adopt new and expanded roles. The AD diagnosis is incorporated, but other critical elements of identity prevail (Bohlmeijer et al, 2011) and the longer and broader narratives do not disappear. Tommy is still contributing, albeit in different ways and he is still a co-author of their marital biography.

The narrative is dominated by 'testing', the particular test of reaching a shared decision about the garden, the 'big test' ahead and everyday tests of patience, competence, stamina and communication. As with *'A Walk in the Snow'*, there is another author at work, bringing testing more sharply into relief. This author introduces a subplot, which

concerns the interplay between Tommy and Grace's notions of a good life and biomedical norms. As a physically fit man, Tommy is troubled by the realisation that the medical profession can brand him as diseased, even though he 'feels like a sixteen-year old'. The inadequacy of his drawings in the memory clinic transports Tommy back to another time when he was labelled deficient and 'put in with the useless lot'. The delivery of his diagnosis generates the same stinging shock as the headmaster's strap. The institution seems unjust.

When Tommy questions his diagnosis by insisting he'd be 'none the wiser', his narrative is co-opted through the presentation of 'indisputable' evidence to the contrary. The plagues and tangles are 'not too bad', 'a touch of frost', but Tommy is unlikely to directly challenge the authority of his diagnosis further. He learnt early in life to do as he was told and carried this into adulthood, as exemplified by his voting habits. He also does not question the judgement that he needs to lose a couple of pounds, instead duly increasing his walking. Aged eighty-five, his body however puts up its own form of resistance to another test, the ability to withstand a higher medication dose. Grace follows medical advice too. The short-term physical health benefits Tommy experiences as a result of 'going back on the fives' come at the price of Grace's disappointment. With the hype and hope of delay compromised, 'further down the road' seemingly draws nearer, causing Grace to step up her preparations. The subplot thickens.

Tommy and Grace follow Beard's (2016) 'pendular trajectory' from receiving a diagnosis through 'accepting' the diagnosis all the way to its third stage, joining a subculture in the form of a support group that reinforces memory loss as pathological through socialisation. Joining the group can be interpreted as a display of self-constancy, consistent with Tommy and Grace's willingness to test out every opportunity that comes their way. Intending themselves into the future as a couple, group participation begins as a means to an end. They seek ways to maintain mutual self-esteem and to make Alzheimer's 'a manageable disability' (Beard et al, 2009) so that they might continue to participate in and contribute to ordinary social life. However, this 'thing that I've got' gives way to 'Alzheimer's' and Tommy increasingly self-identifies as a person with Alzheimer's in his talk. In parallel, Grace becomes Tommy's 'minder'.

Heavily circumscribed and not without consequences, the identity shifts are not straightforward. They encompass resisting, testing the waters, reflecting, delaying, trying again and re-evaluating the pros and cons of membership as unique persons and as a couple. The group offers Grace practical information and support. There are benefits for Tommy too, whose prior understanding of dementia has been shaped by personal contact with people at 'the end stage' and the demise of a character in Emmerdale whose condition deteriorates at the rate of knots, soap time, to satisfy the demands of an audience indisposed to go the distance. Meeting people who are 'living well with dementia' is eye-opening, 'you wouldn't know who had it and who's the carer'. That said, calls to champion their rights are questioned and despite the ready adoption of polarising language, other dichotomising practices do not land well with the group. The pendulum swings. As the study concludes, the narrative has become what novelist Nigel Watts (1996) calls a two-headed monster; two plots compete and it is unclear which will prevail.

Jim and Mary: Doing Whatever Is Necessary

The narrative below contextualises the events and meanings set out in '*Fault Lines*' in Chapter Seven. 'Doing whatever is necessary' is a phrase that Jim and Mary use frequently. I borrow it to represent their efforts to negotiate everyday life. The phrase is a source of contradiction as it speaks to Jim and Mary's aspirations to maximise Jim's independence, to preserve valued ways of life as a couple, to manage Jim's condition as best they can and to follow professional advice. There are different understandings of 'what's necessary' at work and the meaning of the phrase alters over the course of the study. I employ '*doing whatever is necessary*' to structure the following narrative.

When I first meet Jim and Mary, they tell me they are happy '*to do whatever is necessary*' to help with the study. Both quickly point out that Jim's dementia is not the worst of it, rather 'falling' constitutes the biggest problem. Jim and Mary enjoy an affluent lifestyle, which they worked hard for, Jim investing time and energy in the business, Mary supporting Jim's decisions and raising the family at home. They employed only the best service providers and took some big risks. They did whatever was necessary to succeed. Jim quietly accepts his condition, whereas Mary expresses sadness that they aren't able to enjoy the fruits of their endeavours.

When we next meet, I accompany Jim and Mary on a short walk. Mary wants to practice a new grip suggested by the physiotherapist. I learn that Jim fell while out

walking with Mary a couple of years ago, culminating in a debilitating stay in hospital. As Jim is much larger than Mary, she couldn't stop him from falling or get him up. Jim stands exceptionally straight and walks briskly. He was always darting about when he ran the business and walking slowly '*feels unnatural*'. Mary sought professional advice because she wasn't sure how best to grip Jim's arm in a way that is supportive and yet still meets Jim's needs; he doesn't want to appear as though Mary is '*propping him up*'. Mary comments that '*He's very plausible with the physio, but it's a different story when it's just the two of us*'.

When we return, Mary goes to the supermarket and Jim chats to me while he potters around in the kitchen and practices his chair exercises. He has an ongoing bladder complaint, necessitating getting up at speed, which he '*isn't supposed to do*'. He also walks up and down the hall ten times periodically because he seizes up if he sits too long. In between, Jim tells me that when they sold the business the plan was to spend more time at their house in Spain, but they never made the most of it because he got involved in various committees. When I ask why he accepted the offers he replies candidly, '*vanity mostly*'. The stroke club that he co-founded however is something different. A lot of younger people attend, some quite severely disabled and '*seeing them enjoying themselves*' helps Jim '*withstand anything*'. He is keen for me to see for myself and undertakes to '*make the necessary arrangements*'.

As we chat, Jim reflects, '*There's more to me than this; people forget. I've had a good life. This isn't the whole story. I'm realistic*'. He adds, '*I have no strategies, apart from not thinking about it too much*'. The key thing is '*to be allowed to keep doing the things I can do*'. He takes pleasure in making the lunch, heating up some soup and getting a sandwich together. He can do it, he likes to take his time. He enjoys shaving and has '*come to appreciate the feel of a nice, clean shave*'. He has no concerns about cutting himself, having done it for so long, '*I don't need to see my face*'. When Mary returns Jim starts to nod off. He says '*falling asleep is a gift*' and Mary jokes '*You're maybe too gifted*', adding, '*He's always been able to, even when business was hanging in the balance*'. Jim opens his eyes and quips, '*Worrying is wasted energy*'.

I accompany Jim to the stroke club as planned. Jim's submission to the tight arm grips, slow walking pace and his attempts to remain seated other than to relieve his failing bladder strike me forcefully in the wake of our previous meeting. Following Jim's exit from the club, I arrange to meet with Mary and Jim on a Wednesday, but they receive

word of a medical appointment and we reschedule for the Friday. This is one of Jim's days at the day centre, which he can't say he enjoys, but '*accepts as necessary*'. He tells me '*don't let that get in the way*' and assures me that he won't be too tired to meet afterwards.

In the event, the day centre bus is very late. Jim and Mary's daughter-in-law, Denise, drops in '*to see how Mary is doing*'. There has been a deterioration in Jim's condition and he now has carers morning and night. Mary tells me, '*The family are pulling out all the stops*', but she has '*to watch Jim like a hawk*' as he remains fiercely independent. Denise remarks how surprised she is that Jim never complains. Mary suspects it is sleepiness and apathy as a result of his condition rather than serenity; '*The old Jim would be climbing the walls*'. She later reflects '*I wish he would complain, I wouldn't feel it's just me who's fighting against the unfairness of it all*'. Mary and Jim usually go with friends for a fish tea at the golf club on a Friday, but their friends are attending a social function. Last time out Jim had a fall, but the staff were fabulous. Mary reports '*Jim's having more difficulties eating. He keeps missing the plate. He's stabling away at his chips, but it's hit or miss. He won't be helped. He can't see what he's eating. When I looked, he was eating his lemon*'. Mary adds that it's important to still do things as a couple, with other couples. '*They've been good friends, to both of us*'.

When the bus finally arrives, it takes a long time for Jim to get off. Jim has previously told me that he resents being strapped in and driven through the town and he is irritable on entering the house. I learn that he is going for a procedure to inject Botox into his bladder on Monday, the following Monday morning he has to be at eye pavilion by 7:30 a.m. for a cataract procedure, followed by an afternoon appointment with a specialist consultant about an eyelid procedure. He also has to see his Parkinson's consultant because his medication isn't working. When I ask how he feels about the various appointments, he replies, '*It's necessary*'.

The next time I meet with Jim and Mary, I'm dismayed by the change in Jim's condition. He struggles to speak or keep his eyes open. He says to me '*I'm still listening*' and smiles when I talk about football, but drifts in and out of sleep. He had another bad fall and Mary is beside herself. She reports, '*The GP came right away, spent a long time with Jim and referred him to the day hospital, so it's now a waiting game*'. The day centre is also questioning whether it can continue to meet Jim's complex needs. Jim has been getting up at night with his bladder problems, the Botox didn't work. Mary is sleep-deprived

and feels she can't turn her back for a second. It now takes three people to help Jim into the car. Their daughter bought a wheelchair, but Mary struggles to lift Jim over the front step and can't push him far. She tells me that the family are concerned that something will happen to her. Together they have found a care home for visually impaired people, which has a waiting list and they've put Jim's name down. Mary accepts that Jim will need professional care and Jim also accepts this as '*necessary*'.

Mary lets me know when Jim gets an appointment at the falls clinic. She is finding things increasingly difficult. I phone her to see how the appointment went and learn that Jim's diagnosis is being queried. When we next speak she tells me, '*They've decided Jim has a form of Parkinsonism that doesn't respond to treatment*'. Mary freely admits that things are fraught, saying '*We end up shouting at each other*'. She tells Jim he's so stubborn, he retorts that he doesn't want her to care for him. She has never shouted at Jim before and feels wretched. She says '*I have been praying every night, please let me be better, please let me be good*', then something else happens. '*He won't listen to me. He only listens to the professionals*'. She concludes that she is waiting for a date for respite.

I check to see how things are, learn that respite is fixed up in a week's time and arrange to meet Mary and Jim a couple of days beforehand. Jim has been using a urinary sheath and Mary has had a couple of nights' sleep. She's starting to think maybe it's not so bad, maybe she can cope. Then just a few days later, Jim has another fall; he decides to get up, washed and shaved before his carer comes. Mary tries to stop him but can't dissuade him. She turns her back for a second to get some towels in case he falls and down he goes. She can't get Jim back up. The carer arrives and can't get Jim up either. Once again Mary waits, this time for the rapid response team. Mary says, '*They are quite bossy*', telling her crossly that Jim has no balance whatsoever, shouldn't be on his feet, needs to be in bed and see a doctor. Jim stays in bed, he responds to bossiness. The GP comes as soon as surgery finishes and Mary does what everyone has been telling her is necessary, she admits '*I am not coping*'. The GP arranges for an ambulance to take Jim to hospital and he is admitted after a lengthy wait in A&E. He never returns home.

Once again Mary waits, first for a care home assessment, then for the result; the specialist home can't meet Jim's complex needs. Mary finds a care home nearby and waits for a place. She feels Jim is deteriorating by the day in hospital and worries about his mobility. She waits. Eventually Jim moves into the home. The physio tries hard, but is unable to restore any mobility. Mary buys Jim his own wheelchair as she finds him

too heavy to push using the chairs provided by the home. Jim exudes a quiet contentment. He enjoys his meals and Mary hopes he doesn't lose his swallow, she thinks he's suffered enough. She reflects *'I wish it was just normal dementia. You see some of the people here, they are up dancing. They might not remember it or know who they are dancing with, but they look happy. Jim, I don't know, I think his emotions are frozen too'*. Mary visits Jim every day. She says *'People keep telling me I don't have to, but he's still my husband. They say I can get my life back. What life? This life is all I know'*. Mary accepts every social invite on offer to try to fill the void. She does whatever is necessary.

Interpretation of 'doing whatever is necessary'

'Doing whatever is necessary' is initially situated within a timeframe when Jim worked hard to provide a good life for his family, 'good' taking the form of providing financial security. Mary's role was to look after the home and family and support Jim's decisions. They worked independently towards a shared aim and took risks together. This 'couple-specific way of working' (Beard et al, 2009) persists into their day-to-day approach to managing Jim's condition. Jim and Mary continue to 'do whatever is necessary' to participate in everyday life, as represented by finding a way of walking together in the street. Mary wants to protect Jim from falling. At the same time, she is attentive to Jim's need to retain the appearance of what he perceives as a capable man. She seeks a solution that will not look as though she is 'propping Jim up', drawing upon the established habit of employing a professional that Jim will listen to. The physio is able to come up with a grip that satisfies on both counts, but resolving the ethical dilemma of respecting Jim's autonomy and protecting him from actual bodily harm proves less straightforward when extended to other areas of their life.

Jim tries not to think about the future. Of necessity, he is focused on getting through the day, literally one step at a time. The thing that matters most to Jim is 'being allowed to keep doing' the things he can do'. Mary is attentive to this and strives to support him, but there is considerable ambiguity surrounding the things Jim can do safely. Jim is prepared to 'accept as necessary' various inputs from and the restrictions of service providers, including attending a day centre to give Mary a break. Jim and Mary historically have been shared risk takers and Mary has backed Jim's decisions. When Mary's roles and responsibilities veer towards protection, Jim resists. He responds only to the firmer voice of authority. Jim's various submissions to enable him to participate

at the stroke club are in stark contrast to his determination to do things independently at home.

As Jim's condition deteriorates, he 'accepts as necessary' a host of clinical investigations and interventions, but refuses to stay seated; he will be confined to a chair soon enough. Mary cannot turn her back, their enforced togetherness suffocating, not because she cannot pursue her own interests (Vikstrom et al, 2008), but because her role is transformed into watchful hawk. Inevitably, one fall proves fateful, perhaps fittingly as Jim seeks to indulge in the remaining pleasure of shaving the familiar contours of his face. When Jim moves into a care home, it is Mary who is left 'doing whatever is necessary' to fill the void in her life.

Testing assumes a leading role in this narrative too. Jim and Mary actively seek out medical expertise and submit to a barrage of clinical tests in a bid to get to the bottom of and find solutions to Jim's condition. When it comes to the inescapable realities of ageing and death, what medicine can do often runs counter to what it should (Gawande, 2014) and at times there is a risk of confusing care with treatment. Life is increasingly structured by services and Jim's final months at home are dominated by tests and assessments, followed by anxious periods waiting for results. As Jim would say, 'in hindsight'.

The narrative also highlights some tests of friendship, one couple in particular continuing to see Jim and Mary as old friends, rather than foregrounding Jim's condition, sitting together as Jim stabs his plate, misses his chips, eats his lemon and then falls over. They pass with flying colours. However, testing assumes a more insidious form, in that Mary feels she is failing as a wife. Here interpersonal and cultural forces align. She experiences a variant of courtesy stigma (MacRae, 1997), her actions subject to scrutiny, judgement and reprimand; 'Jim shouldn't be walking on his own any more, he shouldn't be on his feet'. Mary is powerless to stop him. Tronto's (1993) distinction between care and protection is instructive. Mary is trying to meet Jim's self-identified needs, but others assert that Jim requires round-the-clock protection from self-harm. Mary is placed in the impossible position in that whatever she does, someone will judge her unfavourably. Each successive fall harms Mary too. Jim's pride and resistance to her attempts to protect him from falling may have been more bearable had she not been branded incapable by those whose arms he was prepared to

accept - 'as necessary'. Mary receives little recognition for her actions, her self-esteem sacrificed in her bid to preserve Jim's.

Medicine is a central organising framework in Jim and Mary's life. They both receive and accept Jim's diagnosis, Beard's (2016) 'pendular trajectory' on this occasion attributable to the oscillations of the medical profession. The couple tell me at the outset that dementia is not Jim's biggest problem and falling is the greatest concern throughout. The rapidity and nature of Jim's decline is devastating, Mary's wish that it was 'normal dementia' bringing a whole new twist to the normal – pathological debate.

Jim's condition does not simply bring unwelcome changes that can be resolved through narrative emplotment, it is a massacre (Gawande, 2014). Jim expresses no sense of injustice about his fate and it is tempting to interpret aspects of his response as indicative of positive narrative closure, his pleasure in the simple act of stirring soup a sign of the serenity of gero-transcendence (Tornstram, 1996). Or perhaps it is Scottish stoicism, 'I am realistic'. Mary however has known Jim intimately for nearly sixty years and attributes this acceptance to the apathy symptomatic of his condition, unrecognisable. In contrast, Mary struggles against the unfairness of being denied the chance to enjoy together the things they worked hard for. She feels alone in this fight and initially wishes Jim would complain, 'the old Jim' would be climbing the walls. Later she comes to see Jim's 'frozen emotions' as a comfort, affording him their own form of protection.

The narrative also underscores the contradictory dimensions of life and in other respects, 'the old Jim' persists. He may be prepared to lose the war, but for a while he continues to fight the battles of daily life. He takes risks, the steely determination once deemed admirable in business circles recast as an obstinate act of will (Ricoeur, 1992). Jim has never worried about the future, his ability to sleep construed as a gift. In the dialectic of sameness and selfhood, shifts in roles and responsibilities within the marriage are resisted, however problematically, and the dichotomisation into care-giver and care-recipient does not occur. Mary engages in her own continued resistance against the expectations of others, that she should constrain Jim, that she should somehow reclaim her life. Jim is powerless in the face of nature (Hoggett, 2000) and Mary is 'still Jim's wife'.

Hector: Paying My Dues

The previous chapter presented the events, happenings and associated meanings identified through *'Meeting the Boys at the Golf Club'*. The narrative that follows connects them with other events and happenings enacted or recounted over the course of the study. *'Paying my dues'* speaks to Hector's traditional values and understanding of the good life as one whereby status, respect and benefits are earned through service to others and hard work; recognition is subject to continued participation and contribution. *'Paying my dues at the golf club'* is a particularly strong thread. Hector's declining health is however impacting significantly upon his levels of motivation and contributions, creating tensions. The plot sets out how *'paying my dues'* comes to assume deeper meanings within the broader context of life itself.

I first meet with Hector just before Christmas and we chat about his early life. I learn that family finances forced Hector to leave school to start work *'on the bottom rung'* in the local mill. Hector reached the position of manager through his own endeavour, earning the respect of the workforce by *'staying connected with issues on the floor'*, then taking the hard route to University in his forties when he foresaw the demise of the mills. His work achievements were the result of paying his dues. His parents were Labour councillors and while his initial formal education was cut short, Hector grew up listening to the political debates that took place around his kitchen table. This political interest developed into a passing fascination with Communism, which he needed to see for himself, resulting in extensive travel through Eastern Europe before the Iron curtain was lifted, to Costa Rica and to Cuba *'to hear Fidel speak'*.

Hector's reason for participating in the study is attributed to *'needing a kick-start'*. He tells me that he lacks motivation, having *'been everywhere and done everything'* he aspired to. While Hector is fully aware of and frustrated by his memory loss, he rejects the diagnosis of Alzheimer's disease. This rejection is reinforced vigorously by Gina, who is adamant the original diagnosis was wrong. To Hector's ineligibility for medication, dismissal from the memory clinic and *'passing his driving test in the A category'*, Gina adds her own assessment that he is *'getting better'* following a regrettable episode of delirium in hospital. The latter tops the evidence hierarchy as she *'knows him better than anyone'*. Both express the hope that passing his driving test will enable Hector to put his recent illness behind him in the New Year. We provisionally agree that I'll accompany Hector to *'pay his dues at the golf club'*, which he

indicates he tries to do at least a couple of times each week, *'seeing the boys, even if the weather is too bad to play'*.

The New Year arrives, but Hector informs me he is *'suffering from the January blues'* and calls off our planned meetings several times. On one occasion, this follows a heavy snowfall and he's unsure who will be at the club, and a second time there is a blizzard. The next time I phone the snow has cleared, but Hector reports *'I've not been good at all'*. He strained his leg at the driving range and can't drive. He won't be going to the club and hasn't paid his dues for several weeks. My offer to drive is declined as he is *'in pain and wouldn't be good company for the boys'*. When he insists that he is *'needing a kick-start more than ever'*, I remind him how much I enjoyed hearing about his travels when we last met, and we agree to look through his travel memorabilia instead.

When I arrive, Gina is attending a keep fit class. In contrast, Hector advises that he's been finding it difficult to get out of bed most mornings. The weather plays a huge part, *'If I hear the wind or rain battering down, I'll just turn over and pull up the covers'*. Previously he was *'up with the lark in all weathers'*. He continues, *'I always said, this is no rehearsal'* – a slogan he saw written on a wall when he holidayed in France. *'You can't be sleepwalking your way through life. This is it'*. Hector tells me that he'd said this to motivate himself to go to the driving range, but because he hadn't been for so long, he overdid it.

Noticing that he has looked out some travel books, I say *'Speaking of France, shall we have a look at these'*? There are assorted postcards, maps, tickets and photographs between the pages. Hector thinks it might be an idea to put something together to show his grandchildren when they visit during the school break. Having grown up on the other side of the world, *'they don't know much about me'*. It is an impressive collection and he delights in retracing the steps of a solo expedition to India to see the Taj Mahal, then to Nepal. While on safe ground in the foothills of Annapurna, the terrain soon becomes more precarious and ghosts from the past surface from the pages of his books, photographs of *'the four musketeers'* on a golfing trip, like all frozen moments, testifying to *'time's relentless melt'* (Sontag, 1978:15).

Hector selects one particularly emotive photograph where the camaraderie between the four men is palpable. He points to his closest friend, Archie, who was *'first to go'*. Archie had gone about fifty yards ahead of Hector up a hill on the local golf course and *'his hands went up and then he dropped like a stone'*. At first Hector thought Archie must

have had a hole in one and was joking, but he didn't get up. He was in a deep coma for two days and never regained consciousness. *'I wept, I knew he was as good as dead. The coma was a buffer for his wife, who had been ill for thirty years'*. It fell to Hector to tell her. *'I used to go on a golfing holiday twice every year with Archie when she went for respite care. I was allowed to go because it was Archie and Gina adored him. Everybody loved Archie, he attracted people like bees round the honey pot'*. Hector delivered the eulogy.

Hector then points to Dougie, who died just over two years ago and was in a care home for about two years before that. *'I went to see him a couple of times every week. Dougie would pull me and whisper that he wished he was away. Then he didn't whisper anything at all; I would come out in tears. It was no life'*. Ten months later, Malcolm died. He looked after his wife, but it took its toll and she had to go into care. Malcolm never got over it and died a couple of months later. Hector concludes, *'I'm the last man standing, the last musketeer'*.

When I next meet with Hector on a Wednesday, he intends to go to the golf club. One of the boys, Hamish, who is in his mid-90s, goes each day for lunch with his son Donald, and Hector and the other boys try to take it in turns to go on different days to provide them with company, usually coming together on a Saturday. We set off, but Hector seems anxious, saying he is *'forcing himself to go, but can't hear a thing'*. His ears need syringed but the wax is too hard. He has drops to put in twice a day to soften it, but it has knocked him off. The car park is quiet and as we walk towards the club house, Hector stops and points to a small crest on the golf course, telling me, *'That's where Archie fell'*. His eyes are teary and he reflects emotionally, *'If he were alive, he wouldn't be lying in bed. He'd be out on that course'*. He continues, *'Whenever I take a shot, I know exactly what he'd say, exactly. We knew each other that well'*. After a moment, Hector says *'Right then, let's go and pay our dues'*. We go inside to find Hamish finishing his lunch. Donald didn't think Hector would be coming, so they'd arrived earlier than usual. Hector struggles to hear what Hamish is saying, becomes exasperated and the visit is brief. He suggests that I accompany him to the golf club on a Saturday next time, after he has had his ears syringed, otherwise *'it'll be a total waste of time'*.

The next time I telephone Hector his ears are still bothering him, then Bill is on holiday. It is over four months since he has been to the club on a Saturday and I wonder if he will ever go back, but we provisionally fix up a date early in April. Hector's morale lifts

with the change of season and his hearing returns. It is a glorious day and when I phone, Hector tells me '*we're back in business.*' Inside the club, I observe that Hector is held in high regard, has been missed, his memory problems are normalised or overlooked, and there is a strong sense of equality among the men, who are '*good company*' and enhance each other's self-esteem. They are '*the last of the Mohicans*'. Hector has also been formally recognised by the club for '*paying his dues*'. This encourages him to resume his Saturday routine and even to venture back out on the course a couple of times.

When I catch up with Hector the following month, he is in the garden. He is tanned, relaxed and looks well and when I say so he chuckles '*There's life in the old dog yet*'. Gina meantime had '*taken a bad turn after overdoing it at her keep fit class*', but she has since bounced back. Hector reports this has been '*a wake-up call*'. He tells me enthusiastically about their plans to take the train up the West Highland Way. Hector says, '*To think I've never done it, when it's meant to be one of the most beautiful railway journeys in the world, on my own doorstep*'. When I next phone I'm staggered as Hector informs me '*Things have changed since I last saw you. Gina is ... seriously ill*'. He sounds distraught and ends '*I'm sorry, I can't help you anymore*'.

Interpretation of 'paying my dues'

During our introductory meeting, Hector impresses upon me that his former work achievements were the result of paying his dues, an inquiring mind and a willingness to adapt. He also uses the phrase '*paying my dues*' in an active sense, suggesting something ongoing, that privileges must still be earned. Hector is however facing a major life change in the form of bodily and mental decline, raising doubts about his ability to intend himself into the future and honour his existing commitments. He indicates that he is lacking motivation and '*needs a kick-start*', but having '*been everywhere and done everything*', no new meanings or experiences seem possible. He hopes to pick up where he left off before the disruption of illness and the form of contribution he attaches greatest importance to entails '*paying his dues at the golf club*'. However, apathy, lingering ill health and the winter weather are all conspiring against him.

Our conversation is permeated with a consciousness of the finitude of life. Hector's concern is not meaning-making through specific actions or events, but rather the bigger task of making meaning of life itself. Hector's continued absence from the golf club

impacts upon his self-esteem as he feels he is letting others down. He believes that he needs to 'keep going' and berates himself when he stops, the golf club becoming a metaphor for life. Hector forces himself to go to the club out of a sense of responsibility to others, but his hearing loss impacts upon his ability to participate meaningfully and ends in frustration. As the study progresses, Hector increasingly talks about his absent friends, particularly his best friend Archie, who died on the golf course 'just fifty yards ahead of him'. At this point, 'paying my dues' assumes new meanings, and I come to appreciate that Hector is motivated as much by 'a responsibility to those who have gone before' (Ricoeur, 2004) as to the men in the club house.

'Paying his dues at the golf club' earns Hector the status of honorary life membership, the respect of fellow club members, and the benefits of new friendships, all of which require ongoing effort and serve as a source of motivation. The golf club and the group of men he meets with offer favourable mediating conditions. His expertise and enduring contribution are recognised and his competence is not questioned. Yet Hector is forced to re-evaluate his life plans, weighing up his continued capacity to contribute to the group meaningfully, to provide the boys with good company and to satisfy his own standards of excellence. The life membership extends possibilities, but the accompanying weight of expectation, of 'paying his dues', is a double-edged sword, an important source of motivation but also a source of self-reproach.

While the issue of formal testing, which featured prominently during my introductory meeting with Hector, does not resurface, there are other more implicit forms of testing at play. Some days, simply getting out of bed is a test of Hector's resolve. In the spring, he resumes his old routine, but there is a delicacy to his return. It was inclement weather and then temporary hearing loss that previously prevented him from attending the golf club rather than memory loss. Hector doesn't know what will stop him in future, more aware now of the defenceless thing-like fragility of the body, experienced in opposition to our purposes and values (Bowden, 1997:112). Then, when Gina overdoes things at her keep fit class, testing her body to its limits, the meaning of 'paying my dues' alters once again. Hector is awoken from his sleepwalk and his commitments change. He visibly relaxes and a holiday is planned, 'there's life in the old dog yet'. Then fate strikes another cruel blow and suddenly it is Gina whose life is in question.

Hector's narrative initially appears to be at risk of foreclosure (Freeman, 2000). The very notion of dementia is an anathema to Hector and he does not take the second step in Beard's (2016) trajectory 'of accepting' the diagnosis of Alzheimer's disease. Instead, a counter-narrative of erroneous diagnosis is advanced and reinforced by Gina. The subject is closed. The risk of foreclosure is in contrast to Hector's earlier life narrative, which boasts a balance of continuity and flexibility. Hector's retirement is recounted as a time of adventure then, having reached a stage where he was content with his commitments and achievements, he had come to view life mainly in terms of continuity, inclined to make meaning through already established identity structures (Bohlmeijer et al, 2011).

The life changes he experiences constitute a major biographical disruption (Bury, 1982), challenging the narrative which has sustained him in recent years and which normally undergirds his identity commitments. Hector, a lifelong critical thinker, is in the unfamiliar position of being unable to provide meaningful answers to the questions raised. Ricoeur (1992:320) highlights the need to take account of deeply concealed forms of suffering that 'go far beyond mishaps and adventures that can be made meaningful through the strategy of emplotment'. Hector's situation provides not only new experiences, but also questions his underlying narrative schemes (Bohlmeijer et al, 2011).

Narrative foreclosure is invariably more than the result of a personal interpretation of one's life (Randall, 2008). People we grow old alongside often co-author the stories we live by. Hector's memory loss is refuted by Gina and normalised by his peers. Co-authorship can also extend to those who have gone before (Ricoeur, 2004) and Archie continues to co-author Hector's narrative, whispering encouragement from the wings. Despite, or perhaps because of the positive messaging, Hector remains anxious that his memory loss is worsening, possibly indicative of an underlying 'paradox of acceptance and denial' (MacQuarrie, 2005). Hector's emotional reflections on his personal encounters with dementia, notably the fates of Dougie and Malcolm's wife, suggest the diagnosis would simply be too painful to think about, even with the support and solidarity of others.

Cultural narratives may also shape our narratives and self-understandings, but as above, Hector's fear of dementia cannot be attributed solely to cultural representations. Moreover, Hector and his peers do not depict old age per se as a life phase that lacks

meaningful roles. There is no indication that Hector is living out the cultural narrative of decline and lack imposed on older persons in general. Rather, his narrative environment is one that promotes a light-hearted yet optimistic attitude. Hector identifies strongly with his age-based male cohort and he is a traditionalist, resisting club reforms. He distinguishes the superior ways of the past and of his peer group, who he refers to as 'the last of the Mohicans', a dying tribe, set apart from the rest of society.

In his talk, Hector consistently maintains the distinction between 'the last of the Mohicans' and 'the four musketeers'. The musketeers are famed for their rallying call, 'all for one and one for all, united we stand, divided we fall'¹⁸. United, Hector, Archie, Dougie and Malcom stood like a band of brothers. Without Archie, one by one they have fallen, leaving Hector 'the last man standing'. He misses his friends and for all his accomplishments in life, reviewing the past can be as painful as looking to the future. Through all the changes and emotions Hector experiences during the study period, he sustains his identity as 'the last musketeer'. It looks as though Hector may be living in 'epilogue time' (Morson, 1994), the important story over, nothing essential will change, when a narrative opening is suddenly crafted, 'a wake-up call'. Then, as quickly as this chink of light appears, the likelihood of an entirely unforeseen ending serves up a further reminder of the pervasiveness of chance and vulnerability as inherent structures of our lives (Bowden, 1997).

Ann and John: Going Back to Place Manor

The following narrative revisits, amplifies and animates the themes identified in '*Managing Expectations*' in Chapter Seven. Place Manor is the scene of Ann and John's first holiday together, they revisited it as part of a recent nostalgia trip and we journey back there, down memory lane, many times during the study. The meaning of 'Going Back to Place Manor' alters over time, connecting with their extended temporal and familial horizons, declining health and the ongoing management of family expectations. 'Going back to Place Manor' is consistent with Ann and John's notion of the good life, unifying their commitment to each other and their continuing contribution to family life. I use 'going back to Place Manor' as a device to explore the negotiation of various obstacles, dilemmas and possibilities over the study period.

¹⁸ The Three Musketeers is a well-known novel by Alexandre Dumas, first published in 1844. The 'fourth musketeer' was D'artagnan.

When I first enter Ann and John's home, John's efforts to keep their memories alive are evident. John tells me the photos dotted around are there *'to remind us of what we had in the past'*. Ann offers lightly, *'Some of us need reminding.'* Having forcefully rejected her diagnosis of Alzheimer's disease, Ann accepts her memory loss and it is not a source of frustration. John does not force the issue of diagnosis and it never comes up in our conversations. During our early meetings, talk often turns to the past, especially *'the magical year'* when they met and fell in love, culminating in their first holiday together to Place Manor shortly after John graduated. It is the setting where John confessed his love for Ann and Ann declared her love for John, *'confess versus declare'* constituting an ongoing point of contention typical of the fiery but friendly debates they routinely engage in. John was overwhelmed by the enormity of this *'confession'*, marring the final days of the holiday and it ended uncertainly. It was Ann who reached out, suggesting by letter that she would be pleased to see John should he *'ever want to visit these parts'*. Thereafter they always talked through their difficulties.

The difficulties include John's nervous breakdown when Ann was about to enter her final year at University. John reflects that Ann was instrumental in his recovery, holding his hand and talking to him. Ann remembers *'little of the actual occasions'* when she visited John, but can recollect feeling that she had nobody to talk to about it, certainly not her parents *'who would have been very upset about the idea of someone being mentally ill'*. Ann and John married immediately after Ann graduated and she briefly took up a post as a teacher, leaving on account of *'a honeymoon baby'*. Another four children followed. When asked about her decision to decline Thalidomide during her second pregnancy, Ann comments, *'Medicine can be marvellous, but can also overreach. I've never thought it particularly wise to interfere with things that are just part of life. I knew morning sickness was a natural part of the pregnancy and would pass'*.

The recollections encompass Ann and John's move to Scotland with their young family when John accepted a civil service post. Unaware of protocols, Ann wrote to a broadsheet newspaper to criticise the *'four-plus test'* employed at that time by grant-aided Scottish schools. When her letter was published, John was informed that he couldn't be political and one's relatives really shouldn't enter the fray either. John was *'supposed to tell Ann off, but would never dream of it'*.

Ann and John tell me that revisiting the past helps them to cope with their current difficulties. There are days when they don't want to get up in the morning, when one of

them is not feeling up to the mark. They often have a lie in. After family visits or trips away, they spend three or four days in bed recovering. Going to bed at night is also *'quite a trial'*, John getting Ann undressed, *'nightie on wrong way round'*, before clearing up which can take over half an hour. The thing that John looks forward to is getting into bed and giving Ann a cuddle. They also talk about their demise, *'whenever that may be'* and know *'the one of who dies last will have a hard time'*. Thoughts of their demise are alleviated by thinking about the family and their hopes for their grandchildren.

During subsequent meetings, talk turns to their hopes for the family and shifting expectations. Anticipating that the family may have questions after he has gone, John develops his reflections on how he and Ann first met into an extended written account of their life together. One son points out an inaccuracy in an early draft and John determines to get his facts straight. He emails me a copy following each revision. John also attaches considerable importance to the marriage vows that he and Ann made to each other, although the Christian significance was not relevant. He expresses a sadness that so many of their grand-children have live-in partners, but have not subscribed to the same sort of vows. Ann quickly asserts that it doesn't worry her at all, and that their grandchildren have thought it through. She states firmly *'I think it is very much up to each person. They may do things that I don't think are quite right, but unless I thought that it was something that was really bad, I just don't think I have the right to impose my way of thinking or my feelings or my ideas'*. John persists that the vows that they made have such importance and relevance in the circumstances in which they now find themselves. He's *'sad that our grand-children may not have that very important peg when they come to the age of 80'*. Ann responds, *'It is something that we've needed, but they may not. It has been and continues to be very important to us, but it's not necessarily something that they will miss'*. John concludes this discussion, *'When I think back to what we were like on our wedding day, my heart just overflows with love for Ann. It's almost a resurrection of the love and affection that we had in those early days'*.

As the weather improves, Ann continues to resist John's efforts to rekindle her aesthetic interests. His suggestion of digging out all the artist's stuff that he bought for her meets with the same response as the proposed greenhouse, Ann would *'be expected to produce something'*. The finer detail of John's plans for celebrating Ann's 80th birthday is also revealed. John had been looking something up online to include in the nostalgia trip write-up and discovered that you can rent Place Manor itself, the main house, so they could have a big family party there. He retrieves an old photograph of

himself and Ann sitting on the breakwater that stops the water flowing up to the door of the house, which *'we'd love to recreate, sixty years on'*. Ann quips, *'I'm not sure we'll improve upon the original'*.

When we next meet, John has experienced some health problems. The family stepped in, but he realises they need an alternative plan going forward. He is also having to manage what he perceives to be a rather heavy-handed response; the family would like Ann and John to access care services now, whereas they couldn't *'tolerate the intrusion'* and are actively seeking more of a contingency plan. The planned trip to Place Manor is also being called into question, because there is no sleeping accommodation downstairs and one son has *'started to get a bit hot under the collar about us climbing the stairs'*. John maintains, *'We have our own ways of managing'*, but their son thinks it's too much.

We talk a little more about their own ways of managing day to day. John has invested in software to block nuisance calls. Ann thinks *'it may be working rather too well'*. John also describes his frustration at having to go through various loops of automated telephone services and Ann observes, *'John is very capable but, looking on, one senses there are so many obstacles to overcome'*. John adds, *'We have youngsters who can help us to deal with the modern world, but others must feel very disfavoured by society'*. John's hearing aids add to the difficulties of speaking on the telephone. He thinks he's *'fairly clued up'*, but the second time the person who sold him his hearing aids visited, his son appeared coincidentally and rather took the lead. John reflects *'He doesn't think I'm competent and that rather arises from the saga of our Riser Recliner chairs'*. John gets up and produces a very fat folder documenting the saga. Ann remarks with a mischievous grin, *'They didn't know who they were taking on'*.

When we meet again, John has rediscovered some correspondence with a Dutch friend charting their early family life and is busy re-establishing chronological order. He delights in reading the letters to Ann and is surprised that he has misremembered a few things and forgotten other details. Ann is unfazed, commenting, *'So much is lost in the mists of time'*. I learn that it has taken Ann and John rather a long time to recover from the exertions of his recent birthday gathering. Some of the family stayed over and he attributes the exhaustion to *'being taken out of our comfort zone'*. He reveals that he and Ann often happily stay in bed until two in the afternoon chatting and watching television, so *'we were quite worn out as a result of having to follow the ... what's the*

word? *The discipline of others?* Ann volunteers “*regime*”, adding *‘I think it gets more tiring each time, doesn’t it love?’*

John goes on to explain that they have reconsidered holding Ann’s 80th birthday party at Place Manor because *‘though I could certainly drive there, we got so exhausted after this blessed birthday party, we decided to cancel’*. He continues that he hadn’t yet mentioned it to Ann, but he just happened to look something up online the day before yesterday and discovered they’ve had a cancellation in the summer for a cottage that would sleep six. Ann asks if he’s trying to tell her something and John floats the idea of going there with one or two of the family. Ann looks as though she is loath to crush his enthusiasm, but responds softly *‘I’m not sure they would want to come’*, to which John offers, *‘Free holiday?’* Ann continues, *‘They don’t get terribly many holidays, love. I’m not sure that’s how they would choose to spend them’*.

Although a physical return to Place Manor is taken off the agenda, Ann and John continue to revisit it through their memories. As we are wrapping up the study, John returns once more to *‘the magical year at University’*, describing the *‘wonderful atmosphere, lots of green, lovely campus.’* Ann tells him blithely that she thinks he’s *‘idealising it a bit’*. John pleads, *‘Not idealising, romanticising’*, but Ann stands by her word choice, teasing *‘I think you are rather presenting it as ideal. I can remember far more times worrying about the maths. Maybe you found it easier’*. John is undeterred and insists, *‘Oh it was magical, I wouldn’t pick any other time –and I was disposing of another girlfriend too,’* at which point Ann interjects humorously, *‘There, you see, the truth will out’*.

Interpretation of ‘going back to Place Manor’

The meaning that Place Manor holds for Ann and John is immediately apparent. It is the place where love and the prospect of married life first surfaced, and where it almost ended on account of John’s idealism. Life could have been very different had it not been for Ann’s practical intervention and had they not developed the ability to talk through their difficulties. ‘Going back to Place Manor’ and the challenges faced prior to their marriage through conversation and photographs serves to keep Ann’s memories alive and fosters new meanings that help them to cherish the present moment and sustain them both going forward (Molyneaux et al, 2012). Ann and John are able to ‘live off the past’, and draw upon not only their memories, but also their reflections upon them as a kind of ‘biographically accrued capital’ (Mader, 1996:43) enriching their inner worlds.

They identify as a unit, equal partners, co-dependent, working together to co-construct their unfolding narrative. They follow a pattern established over many years, each appreciating and respecting the other's distinctive qualities and often gender-specific contributions in a way that maintains mutual self-esteem.

'Going back to Place Manor' assumes a more literal meaning, with Ann and John making the long road trip back there, rekindling old feelings and generating fresh memories. The memories and associated meanings are so important to John that he wishes to entrust them to successor generations, keeping them alive into the future and passing along whatever wisdom they may embody (Randall and Kenyon, 2000). This is a very distinctive type of contribution to family life grounded in a different mode of citizenship, namely an aspiration to help the next generation on their way to being good citizens. John captures his reflections in writing and this is connected to the shared wish that they'd spoken more to their own parents, further stretching concepts of time. Revisiting the vows that Ann and John made to each other also holds significance, strengthening the commitment to love and to cherish 'til death do us part. While John wishes more of their grandchildren would make similar vows, Ann accepts that the vows may not hold the same significance for their grandchildren and they may not miss them in future. In so doing, she draws on her own mother's influence, replicating her commitment to giving people space to find their own meanings, thus demonstrating a different way of passing things on.

The meaning of 'going back to Place Manor' alters again when John conceives of the idea of celebrating Ann's 80th birthday there with the extended family. They have a large family who lead busy lives and have their own commitments and it is difficult to get everybody together. John thinks it is right that they assume this responsibility, helping the family to appreciate that they are part of something bigger, identifying as a different type of unit. Holding the party at Place Manor speaks to the forging of an increasing sense of connection with the broader horizons that border our existence (McAdams, 2006) characteristic of life review. John, the romantic, is enthused by the plans, while Ann, the pragmatist, remains cautious, aware of the necessary mobility in life plans involving the family on account of their busy lives. She *remembers* being a busy mother too.

The decision not to go back to Place Manor is a response to family expectations of Ann and John and concerns about their capabilities. John initially resists anxieties about

managing the stairs, but later comes to acknowledge the limits of their energy levels. When John suggests making the trip to a single-storey cottage with just a few family members, it falls to Ann to highlight the need to manage their expectations of the family, who have limited holidays and may have other aspirations. Once again, John is the romantic idealist, Ann the practical realist. This pattern persists when they revert to going back to Place Manor and the past that surrounds it in their memories, John waxing lyrical about the magical year, Ann wrapping up with a witty one-liner rooted in the practical matter of passing exams.

Formal testing plays an unusual part in this narrative, cognitive testing three years earlier proving an affront that 'didn't touch the surface of the changes in Ann's intellectual reasoning'. Rather, the narrative serves up a reminder of the enduring nature of our hyper-cognitive culture (Post, 2000) in the form of Ann's letter of complaint about the testing of four-year olds in the 1960s. John faces daily tests of stamina and competence, admitting to finding the modern world intellectually demanding. Competence is also scrutinised and called into question by family members and although John jests that perhaps they have grounds, the shift in his positioning is hurtful. Alongside the family's expectations of Ann and John and their expectations of the family, Ann engages in her own management of expectations. Always a high achiever, Ann's resistance to her diagnosis finds parallels in her resistance to engagement in activities where there might be an expectation that she 'produces something' that could be evaluated. Most significantly, the narrative is dominated by the ability of the marriage, and the love on which it is based, to stand the test of time.

There is little space for memory loss let alone dementia in this narrative. Ann never takes the second step in Beard's (2016) trajectory of accepting the diagnosis and it simply doesn't arise within the flow of conversation, other than through the occasional nonchalant remark 'some of us need reminding', or 'so much is lost in the mists of time'. In the past, Ann has been prepared to question authority, not only challenging the appropriateness of standardised testing in schools, but also highlighting the demonstrable overreaching of the medical profession into the natural course of life. I would like to interpret her response to her AD diagnosis in a similar light, but Ann grew up in a time where strong family resistance to mental health issues left her feeling isolated. Her response is perhaps more complex.

John accepts the diagnosis, occasionally swinging on Beard's pendulum to question it on account of the acuteness of Ann's observations, but day to day it is of little consequence. John's concern is Ann's happiness and keeping the conversation going. 'Whatever biological substrate may have existed in her brain', since John was 'focused on her mind and her consciousness and her pleasures', he 'did not know and did not care' (Gullete, 2014:132). This reaffirms that partners do not need to react the same way to a diagnosis to be coping "well" as a couple (Beard et al, 2009).

The active ageing discourse is also resisted jointly, and although both Ann and John were previously heavily involved in civic work, they are now quite prepared to stay in bed until the afternoon or watch TV all day when they are tired. They form a united front against the regimes of others, shirking the idea of formal care services and taking steps to exclude nuisance callers. Perhaps the greatest act of resistance however is demonstrated by Ann as she engages in conversation. A terrific wordsmith, Ann's wit and gentle curbing of John's romantic idealism call to mind Gullette's (2014) account of her mother churning up 'the wisdom – dementia binary'.

Chrissie: Doing the Christmas Boxes

The following narrative contextualises the themes identified in '*Sink or Swim*' and '*Piccadilly Circus*' in Chapter Seven, expanding upon the contrast between Chrissie's experiences in the private and public spheres. 'Doing the Christmas boxes' is an activity that exemplifies Chrissie's particular brand of citizenship, which I interpret as a form of corporeal generosity (Diprose, 2002). The deeper meaning of 'doing the Christmas boxes' is only revealed to me towards the end of the study and I use '*doing the Christmas boxes*' to symbolise the deepening of my understanding as the boxes fill up with little delights over the study period.

The first time I visit Chrissie, I am struck by the array of shoe boxes wrapped in assorted Christmas paper neatly stacked against one wall of her lounge. She informs me that she makes up Christmas boxes for the '*orphans in Africa*' every year, starting in January. She's '*got the whole family doing them*'. Whenever she goes to the shops she picks something up and loves watching the boxes gradually fill up over the year. Chrissie shows me a photo of the beneficiaries on her ipad, saying it makes her realise how lucky she is. 'Being lucky' is a recurring theme in Chrissie's talk, despite what strikes me as a lifetime of hardship.

During our initial meeting, I am introduced to Craig, who Chrissie treats as one of her own large family, having assumed responsibility for him as a baby when his mum was battling alcoholism nearly eleven years ago. She confesses, *'He's the special one'*. I'm told that Craig is needing her less as he gets older, but there's still the odd time when she thinks, *'What would he do if he didn't have me'*? I wonder. Craig is also present during our second meeting. On both occasions, it's clear that he adores Chrissie, who he calls *'Granny2'*. All Chrissie's great-grandchildren do.

As we are driving back from the leisure centre, Chrissie announces that she's going on holiday to Turkey with Helen; the hotel accommodation came free when she had her gutters done. She's aware of the terror threat, but shrugs, *'Life's too short. It's a bonus ball'*, as she's already booked to go to America in September with James, Frank and Helen. Chrissie can't wait for the trip to the States, as this will be the first time they've holidayed together. They've decided to *'go for it'* while Chrissie's still able to enjoy it.

Chrissie reflects, *'I don't think I'm getting worse, but you never know when it will kick in'*. She adds that her GP doesn't think she's getting worse either, but that's because she practices the *'100-7'* test every day. *'I'm faster now than when I was at school. 100-7 is 93, 93-7 is 86. When I get to 30 I relax'*. She laughs, *'If she changed it to '100-6' I'd be snookered'*, adding *'Mind you, last time she drew a pillar and I had to copy it and overlap her drawing. I drew it okay, but it didn't overlap. She asked me to draw the 50p shape too, but I missed a corner. I knew straight away that I'd made a mistake, but it was too late'*. I learn that the GP is *'great, not that bothered about the scores'*, unlike her consultant. The GP is *'more interested in me and how I'm getting on'*. Chrissie has been practicing both tests and is confident she'll get them right next time: *'I don't worry if I can't do it the first time, if I can get it right when I go back then I know I'm winning'*.

It is a beautiful spring morning when I next meet with Chrissie and she takes me out to see what's she's being doing in the garden. Her borders are immaculate and she claims they're *'the best they've ever been'*. As we look at the plants, she tells me that Helen is moving in and Natalie (Helen's daughter) and her new partner are moving into Helen's house with the baby. Chrissie says *'Helen was always going to move in with me, we're just doing it a bit sooner to give Natalie and her new fella a chance. He's fair away with her. She's never had anyone like that'*. I remark that it must be a big change for both of them. Chrissie replies, *'Well things are always changing. Like Craig, he used to come to*

me every day, but he doesn't any more. He loves his mum and that's right. She's been better. But, well he's number one, I can't help it'.

We drive to the garden centre where a purple flowering plant catches Chrissie's eye. The label advises to protect from frost and Chrissie checks the weather forecast on her phone. It doesn't sound good for the weekend, so she decides to leave it. She has however spotted a mixed box of plants that will be perfect for Elsie's tubs. Chrissie thinks Elsie needs cheering up as Jessie, two doors down, has moved permanently into a care home. Elsie thinks she'll be next, but Chrissie hopes not, admitting *'I'd be lost without her'*. Chrissie reports that she's *'splashing the cash'* as she won £140 at the bingo and split it with her friend. We are going to Chrissie's favourite discount store later, the bingo win enabling Chrissie to *'go to town'* with the Christmas boxes. She says, *'That reminds me, I'll need to get my lottery ticket. If I won, I said to Frank I would give it all to Africa for one of the water projects. He said, oh no you would not, because we'd say you had Alzheimer's and didn't know what you were doing, and we'd put you in a home'*. She laughs, concluding, *'He probably would'*.

I'm informed that going into a home doesn't worry Chrissie, *'I've worked in them, just hopefully not too soon'*. She points her finger, adding *'although'*. The *'although'* relates to forgetting to collect Jackson, her great-grandson, from school, only realising this when his mum, Gillian, phoned to see how he had got on. *'I ran. It's just five minutes in the car, but I was more than fifteen minutes late'*. Jackson wasn't worried, suggesting maybe granny2's car wouldn't start and she'd had to walk. Chrissie told his teacher about her Alzheimer's. She found that hard, as she doesn't want everyone at the school knowing her business, but didn't want them to think she didn't care. She concludes, *'I was just cleaning my cupboard. I need Gillian to remind me'*.

Chrissie drives on to the shopping complex, taking us through the small town where she used to live to avoid a busy roundabout, telling me *'I much preferred living here. James says you can't turn back the clock. He's right'*. She describes watching the kids getting dressed in front of the coal fire as *'happy memories'*, adding *'rose tinted'*. I learn that Chrissie left her first husband for several months after an episode of domestic violence when the kids were young. Helen had told an old neighbour that Chrissie left him because she couldn't stand it, but left her and her brothers with him. That was fed back to Chrissie and it hurt, but they've talked about it recently. The family know why she did it, *'they don't hold it against me'*.

We head into a sports shop to buy some joggers for Craig. Chrissie is unsure about the labelling – what is a medium boy? Eventually a lycra-clad woman appears and Chrissie approaches her to check she has the right size. The woman confirms this, instructing *'If you wait there I'll bring the card reader'*. She disappears for quite some time and I note there is no queue at the cash desk. Eventually she returns, asks Chrissie for her card and Chrissie enters her pin hesitantly. The woman asks Chrissie if she wants a paper or email receipt. Chrissie asks for both, which is met with a grunt. Chrissie supplies her email address effortlessly and is advised that she needs to go to the cash desk to collect her paper receipt. As we walk across Chrissie says, *'See that confused me, that's the sort of thing that would get me in a flap if you weren't here'*. I admit that I'm confused too. Chrissie puts her paper receipt in her bag, remarking, *'Usually I'd get uptight thinking about where to put this in case I need to take them back, but if I get the email, that takes the pressure off'*.

I meet Chrissie just before her trip to Turkey. She had thought we might go for a drive to the charity shops, but James has her car for a few days. It's been raining heavily all day and she admits that she's not that keen on driving in the rain anyway, plus she's agreed to look after Jackson. She invites me into the kitchen to see the cream cakes she's bought for us, and I realise that she must have walked to the bakers in the rain. There is one for Elsie too. While the kettle is boiling she says *'come and see what you make of this'* and we go through to the lounge. I notice that the Christmas boxes are filling up nicely, but Chrissie points to some bedding, a collection of carrier bags and a small suitcase. It transpires that one of her grand-daughter's friends is homeless, having walked out on an abusive relationship and is going to stay at Chrissie's while she's on holiday. Chrissie tells me she's been in that position, *'I wouldn't see her on the streets'*.

Jackson is desperate to go to the newsagents and keeps asking, *'When is the lady going?'* Chrissie replies *'If you're cheeky, we'll not go at all'*. She shakes her head, grumbling *'They're all like that, the only one I don't get cheek from is Craig'*. She goes on to say that Craig's not around as much. *'That's fine. It's good that he's got more of his own pals and wants to spend time with them. I need him more than he needs me now'*. She adds that Natalie will be pleased, explaining that she had hung photographs of herself, Helen, James and Frank in her bedroom, but *'felt there was a gap'*. She put Craig's photograph up but when Natalie saw it, she was furious, found a photo of Kevin and put that up instead. Chrissie concludes, *'She thinks I'm trying to replace him'*.

Chrissie hasn't spoken about Kevin since telling me about his death in a very matter-of-fact way when we first met. Today she surprises me by telling me that Kevin was *'the nicest natured'* of her children, *'he was special to me too'*. She goes on to talk about Kevin at length, concluding with a heart-breaking account of the day he died, *'we'd been waiting on it happening for years. He was a tragedy in the making. I think about him every day'*.

I catch up with Chrissie when she returns from Turkey and she's already looking forward to her holiday to America, telling me she'll stock up on Halloween stuff when she's there and then she'll need to start *'gearing up'* for Christmas. I have seen photographs of Chrissie dressed in her elf costume hosting the annual children's Christmas party, which has *'grown arms and legs'* - this year, she's hiring the community centre. Chrissie asks if I've seen her cake photos and produces an album. They are the Christmas cakes of my youth, wrapped in paper frills, covered in snow-peak icing and topped with an array of plastic decorations. Chrissie opens a cupboard and digs out an old shortbread tin where the decorations are stored, telling me they're not expensive, but as she makes six cakes, she asks for them back, but doesn't always get them. We look through the assortment of Santas, snowmen and reindeer before Chrissie finds her favourite, a glittery Christmas tree with a yellow present nestled in the branches.

The discovery of the tree prompts Chrissie to tell me that she never saw much of her real dad when she was young as he had his own family and his wife wasn't keen, but she went to his house one Christmas. Chrissie was wearing a hand-me-down dress that was too big and white socks. Both socks had the same pattern, but must have been different sizes as one was shorter than the other. She recalls walking into the hall, which had a thick red carpet and a *'Christmas tree with fairy lights that went all the way to the ceiling'*. Her eyes glisten like the glitter on the tree as she continues, *'In the tree, was a present, wrapped in paper with baubles on it and a sticker that had my name on it. I'd never had a wrapped present before'*. The others were playing games in the living room, but Chrissie just stood there, looking up at this present. She smiles, concluding *'I couldn't believe my luck'*.

Interpretation of 'doing the Christmas boxes'

The importance Chrissie attaches to 'doing the Christmas boxes' becomes apparent during our initial meeting. Chrissie identifies strongly with others less fortunate than

herself and giving to others reminds her of her own good fortune in life. A more generative future is also alluded to, as Chrissie is delighted that 'the whole family' are now doing the Christmas boxes – the pleasure to be derived from giving to others is something that she has passed on.

As the study progresses, the boxes start to fill up and so does the well of examples of Chrissie's generosity to others. Their association with her own good fortune becomes increasingly apparent. Chrissie's account of receiving her first wrapped Christmas present as a small child is framed equally positively. There are different ways of looking at situations and Chrissie's reflections, by her own admission, are 'rose-tinted'. The practical value of the notion of the 'narrative unity of a life' is evident. Like all life narratives, Chrissie's story is a mixture of fabulation and actual experience (Ricoeur, 1992:161). Ricoeur (1992) emphasises the connection the narrative makes between estimations applied to actions and the evaluations of persons themselves. While his notion of 'life plans' places an accent on the voluntary side of existence, the notion of 'narrative unity' underscores the organisation of the mix of intention, causes, happenings and chance that we find in all stories (p178).

Ricoeur (1992) also stresses that we need the help of plots to articulate narratively retrospection and propection. Chrissie borrows the plot of a good luck story and her AD diagnosis and future are contextualised within this. By narrating a life 'of which I am not the author as to its existence, I make myself its co-author as to its *meaning*' (p162). Against the 'narrative unity of a life' lived so far, Ricoeur (1992) posits the possibility of the good life, which comprises 'the nebula of ideals and dreams of achievements with regard to which life is held to be more or less fulfilled. It is the plane of "time lost" and "time regained"' (p179). Chrissie is aware that 'you can't turn back the clock' but she is fully committed to making the most of the time that remains 'while she's still quite good'.

Ricoeur (1992) also draws attention to the 'entanglement of life histories'. The many interdependencies in Chrissie's life result in numerous narrative threads. In particular, Chrissie's relationship with Elsie forces me to revisit my understanding of reciprocity in light of the notion of 'corporeal generosity' (Diprose, 2002). Chrissie indicates that she'd be lost without Elsie. Chrissie enjoys Elsie's company, Elsie isn't lucky enough to have a daughter, Chrissie never knew her own mother; there are layers of complexity. It isn't simply that Chrissie's contributions are recognised by others, her own self-esteem

is intertwined with her esteem of others. This extends Ricoeur's (1992) consideration of solicitude to engage with the notion of similitude.

One particular narrative thread that develops late in the study concerns Chrissie's son, Kevin. For Chrissie, thinking about Kevin is an everyday activity, but it is not an activity that can be observed. And it is not an 'activity' that she was initially prepared to share with me. There are regrets within Chrissie's story, notably leaving her children with her violent first husband when they were young. She has had the chance to make amends to the three that remain, on the plane of "time regained", and they are holidaying together, replenishing the cupboard where happy memories are stored, like cake decorations. But there has been no opportunity to make amends with Kevin. Instead, it is another small boy who came into her life when he was in need who has become 'the special one'. Craig, if not taking Kevin's place, allows Chrissie to make amends in a different way. Chrissie can see that Craig is becoming increasingly less reliant on her and, while admitting that she'll miss him, she accepts this as right – he loves his mum and he has friends. Chrissie has contributed to these developments enormously. It is another form of citizenship.

Testing features in Chrissie's narrative too. Whereas the formal cognitive testing conducted by her consultant was resisted because he made Chrissie 'feel like a performing monkey', the regular testing by her GP is not unwelcome. Chrissie practices the tests daily and uses them to gauge her own performance, to see if she is 'winning'. Another point of departure is that while other participants have found technological advancements testing, Chrissie embraces them. She is adept in the use of social media and finds the emailing of receipts reassuring. When situations in everyday life do prove testing, she seeks ways round them rather than withdrawing; she learned to sink or swim at an early age and is a graduate of the school of hard knocks.

Dementia plays its part within the narrative. Chrissie variously accepts, negotiates, exploits, hides and resists the AD label and its connotations in strategic and tactical ways. She experiences anxiety when she is away from home and there is a tendency to attribute uncertainties to the condition. She is upset that she forgot to collect Jackson from school and didn't want his teacher to think she doesn't *care*; Chrissie cares a great deal. She reveals her diagnosis to people outside her social circle reluctantly, to explain omissions or to make life easier going forward. In so doing, Chrissie generally finds

creative ways to navigate around the AD label in response to the exigencies of the situation.

In Beard's (2016) terms, Chrissie takes the second step of incorporating the AD label into the complex folds of her identity, but does not take the third step of joining a support group. There is no need for one. Chrissie has an extended support network. Further, memory loss is practically problematic, but not a personal disaster. AD does not dominate her life, a life characterised by turbulence since birth. Chrissie's life plans have always had a degree of fluidity. There are references to an uncertain future, but the AD diagnosis is just the latest stone cast into the pond, a pebble rather than a rock, sending out a few ripples, but not enough to stop her fishing. The many interdependencies that characterise Chrissie's life ensure that she has other ongoing concerns and the future holds welcome possibilities too; 'Life's what you make it'.

At times, I look at Chrissie and I can still see that little girl staring up at the Christmas tree. Things I have taken for granted throughout my life have always been just out of her reach. Yet, when she says that 'there have been more good times than bad, a lot of laughs too', I sense this to be true; I've experienced a lot of laughs with her. Her extended family adore her and they co-create the narrative, but Chrissie remains first 'author' of its meaning. They constitute a different kind of 'unit'. There is a real respect for what she's done and who she is, who she continues to be. Her contributions and achievements are recognised and she recognises the contributions of others. She is still Granny2 and Chrissie still cannot believe her luck.

Reflections and Way Forward

The five narratives presented in this chapter seek to preserve complexity and diversity, providing nuanced accounts of the negotiation of everyday life in storied ways. The configured narratives depict the part that 'dementia' does or does not play in the participants' lives. Consistent with the wider literature, they articulate different ways of responding to and living with dementia in later life. In this study, 'ordinary', everyday life and the ongoing achievement of a 'good life' were not associated with whether the person integrates dementia-as-disease into their identity, or construes dementia as forgetfulness or part of ageing. Nor were they dependent on both members of a couple responding the same way. However construed, diagnosis in itself was not necessarily beneficial and post-diagnostic supports were not always appropriate. Where taken up, the supports proved helpful, but were not without issue. Diagnosis also did not

necessarily constitute a (or the) major disruption in the person or couple's life.

Together the narratives lend support to my overarching argument that the different ways of responding to and living with dementia require equal consideration and the suspension of assumptions.

The risks of making normative assumptions about what people need or what should be important to them include neglecting other aspects of the person's life that they are seeking to maintain or improve, and overlooking their particular contributions.

Baldwin (2005:1027) has argued that to challenge the disabling master narratives of dementia, counter-stories that are individual, enabling and meaningful need to be both constructed and realised. The study sought to enter the domain of the possible and the configured narratives depict shifts over time, engaging with both construction and realisation. They do so through the ordering and creative functions of narrative, charting possibilities considered, and who and what people are actually able to be and do. In different ways, the participants seek to make and make contributions to their own lives and the lives of others, in line with their varied life priorities and retained capabilities, by being and doing. There are diverse ways of practising and realising social citizenship.

The narratives highlight difficulties where dominant Western assumptions about what constitutes a capable man prove hard to sustain. For women, while Chrissie and Ann have very different backgrounds and capabilities, both underscore the place of luck and chance in life and their self-esteem has been closely associated with appearance and caring capabilities, which again can be hard to sustain. The narratives also depict forms of citizenship-as-practice that are relational, creative and generative, from honouring those who have gone before, leaving a legacy, actively passing on traditions, knowledge, values and practices, to quietly modelling ways of being, for the benefit of partners, family, friends, associates and unknown others. Many of these practices are located in the mundane spaces of daily sociability (Neveu, 2015) and in the private realm. The narratives in themselves constitute a form of resistance to dominant cultural representations that valorise independence and public life, and catastrophise dementia as a 'horror story'.

The narratives also convey other diverse forms of resistance to the ascribed, deficient identities of 'old' and 'impaired'. These include the development of meticulous management strategies, active and purposeful management of the expectations of self

and others, rejecting the diagnosis and developing counter-rationales, deploying humour, carrying on regardless, selective withdrawal and disclosure, churning up the wisdom – cognitive impairment binary, quietly questioning authority and forcefully pointing out why specific reductive practices are problematic.

The narratives do not however replace the dominant narrative of decline with exclusively positive counter-narratives that might risk inadvertently perpetuating the ‘action bias’ that has questioned the inclusion of people with more advanced dementia in the category of ‘person’. Rather, they attend to the mix of acting and suffering, activity and passivity, strength and vulnerability, joy and sadness, love and loss, luck, intention and happenstance that characterise all human lives, with or without the phenomenon called dementia. Often bodily impairments such as imbalance, hearing loss, visual impairment, chronic pain, continence issues coupled with an inability to move at speed are as, if not more problematic than cognitive ‘dysfunction’. Together the narratives have something to say about the human condition and are offered as a response to the urgent need, identified in Chapter Two, to bring humanity back into considerations of ageing and dementia.

By choosing to conduct a Narrative Inquiry, I did not want the participants to fade into support roles to illustrate particular themes. I set out to look for patterns within the accounts rather than across them. Yet the spectre of testing cast a shadow across all narratives, albeit in different ways, that could not be ignored. The initial cognitive testing that culminated in diagnosis is a common point of anchorage, which all participants with dementia found reductive and demeaning. However, another commonality is the more implicit testing in the form of informal evaluations embedded in the various ‘practices’ in each person’s everyday life and the local cultures in which they are enacted. In different ways, such testing plays a part in the co-construction and conditionality of future expectations, especially with regard to the continued capability to contribute to ordinary social life. Some environments and practices offer more accommodating constituent rules and expectations than others. In this study, Chrissie’s family challenged my perceptions of risk, and the local golf club, characterised by a purposeful commitment to appeal to men and women, young and old in order to survive and flourish, fared better than environments designed with the needs of specific groups in mind.

Within the narratives, there are also accounts of testing across the life course, ongoing tests of love, friendship, endurance, patience and commitment, and specific tests passed and failed, recollected in light (or in the shadow) of testing in the here and now, aiding understanding of each person's situation as a whole, and playing a part in the ongoing construction of narrative identity. Memories are not only purposefully recollected, but are often evoked spontaneously in response to present stimuli. The memories triggered can impact upon or detract from the larger task of making meaning and constructing positive understandings of the value of life as a whole. I look again at the narratives through a critical lens in Chapter Nine as part of a broader reflection on the contribution of the study and then consider the translation of the research outputs into practice.

Chapter Nine

The Personal is Political

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, 1978:3)

Overview

In this concluding chapter, I bring together the different elements of the thesis, recapping briefly on the story so far before reflecting upon the research questions through a social citizenship value lens and drawing conclusions. Through this discussion, I add different layers to the overarching argument of the thesis, namely that the many alternative ways of understanding and responding to ‘dementia’ or memory loss in later life require equal consideration and the suspension of assumptions. In so doing, I demonstrate that the thesis makes new contributions to knowledge in several respects, empirically, by bringing fresh and more nuanced understandings of the everyday lives of older persons living with dementia, and also theoretically, methodologically and with potential societal implications.

The story so far

In Chapter One, I expressed the concern, based on practice observations, that assumptions regarding what older people living with dementia need, or what should be important to them, can obscure other aspects of life that they may wish improve or maintain and thus restrict their opportunities. Such assumptions may overlook the material circumstances of their lives and can also result in their contributions not being recognised. Further, I observed that persons resisting the diagnostic label of dementia or departing from the narrative of loss were often doubly-labelled as lacking awareness or in denial. My engagement with the literature in Chapters Two and Three heightened my concern and my resolve to address it. Particular influences included fresh critiques of the biomedicalisation of ageing and the rapid expansion of its technologies into the domain of cognitive impairment, empirical studies examining the complexities of so-called ‘acceptance and denial’ and theoretical arguments for extending considerations

of citizenship-as-practice into the realm of ordinary social life and attending more closely to forms of misrecognition. Responding to persistent pleas for ordinariness from older people living with dementia and detecting a growing interest in 'ordinary doing' across disciplines, the study set out to explore how older people accomplish an ordinary, everyday life with dementia. Employing the narrative-in-action methodology developed over Chapters Four and Five, I addressed the following questions:

1. How do people (living with dementia) variously:
 - Construe 'everyday activity' and 'everyday life'?
 - Enact the activities that comprise everyday life?
 - Make meaning *in and through* these activities?
2. How do people (living with dementia) variously negotiate and make sense of the obstacles, dilemmas and opportunities of everyday life *through* time?
3. How is memory loss / dementia incorporated into the unfolding narratives and identities of people (living with dementia)? What part does 'dementia' play within these narrative configurations?

In responding to the above questions in Chapters Six to Eight, the study makes a preliminary contribution to new knowledge by bringing fresh and more nuanced understandings of the ordinariness of the everyday lives of older persons living with dementia. In the sections that follow, I employ a social citizenship value lens to review and build upon this contribution to address the remaining research questions:

4. How might the narrative-in-action methodology enhance future understandings of the (narrative) citizenship of people living with dementia?
5. What are the theoretical and societal implications of the study from a social citizenship perspective?

EXPECT: Bringing a Social Citizenship Value Lens to the Study

To facilitate the discussion, I utilise the EXPECT framework purposefully developed by Bartlett and O'Connor (2010:95-119) as a heuristic device for locating social citizenship in research practices in the area of dementia studies. The authors begin with the premise that 'we must EXPECT that men and women with dementia can and should be actively involved with the generation and translation of new knowledge' (p95). The application of the framework facilitates consideration of how key components of social

citizenship, notably freedom from discrimination and having opportunities to participate and grow, might be realised in different phases of designing and conducting social research, from debates as to what constitutes evidence through to the translation of research into practice, as set out in Figure 9.1 below.

Figure 9.1 EXPECT Framework for locating social citizenship in research

Evidence-based practice reconsidered: privileging people's stories

eXtended research agenda: beyond health and social care quality

Participatory and creative methods

Ethical debates and dilemmas

Critical Lens

Translation of research into practice

Bartlett and O'Connor (2010:95)

Following this framework, I first consider the contribution of the study to (re)consideration of what we regard as evidence. In particular, I revisit the theoretical underpinnings of the study methodology, namely Ricoeur's (1984; 1992) comprehensive narrative theorising, and underscore its capacity to elevate the status of narrative as a valued form of evidence with ontological, epistemological and ethical significance. I also reflect upon the study's use of insights from narrative gerontology to underscore the value of narrative in later life and summarise the ways in which the study responds to the distinctive challenges that narrativity can present in dementia studies. My attention then turns to the study's contribution to extending the research agenda, first by purposefully framing the research questions to ask how an ordinary life is accomplished, suspending assumptions of difference and bracketing biomedical labels to counter the occlusion of everyday life and its meanings. I then consider the insights gained through the study's sustained attention to temporality.

The application of the EXPECT framework then focuses on the narrative-in-action methodology and I look closely at choices made in planning and conducting the research and the extent to which these choices created **p**articipatory possibilities for citizens of that other place, the ageing and dementia landscape. The review of the methodology encompasses **e**thical considerations and entails 'care full deliberation' (Barnes, 2012) about the creation, ongoing negotiation and ending of uniquely

constructed relationships with the research participants, including questions of power, reciprocity, mutuality and authenticity.

I extend the application of the EXPECT heuristic to the fruits of the Narrative Inquiry, as set out in Chapters Six through Eight, through a critical lens. I reflect on the study's aspirations to challenge the assumed homogeneity of 'the dementia experience' and to enter the domain of the possible. I consider the opportunities for and barriers to participation, contribution and growth in ordinary social life and reflect on particular forms of misrecognition.

Finally, I present my conclusions, drawing upon the recent developments in dementia studies reviewed in Chapters Two and Three to consider the societal implications of the study. I offer recommendations for the translation of the study outputs into practice in a manner consistent with Narrative Inquiry principles, including consideration of the limitations of the study. In considering how I hope the narratives will be received, I return to Ricoeur's (1984) narrative theorising and his notion of 'refiguration'. I end by considering how the opportunity to spend time with the older persons who took part in the study prompted me to 'refigure' my own thoughts about ageing and time.

The Evidence Base Reconsidered: Securing a Place for Narrative

The first aspect of the EXPECT framework calls for evidence-based practice to be reconsidered if research practices are to be more consonant with social citizenship values. Bartlett and O'Connor (2010) highlight the need to challenge the continued privileging of methods that limit or discount the voices and experiences of people with dementia, asserting that personal stories are a valuable form of knowledge within a continuum of evidence. The authors also draw attention to narrative techniques that locate subjective experiences within a socio-political and cultural context. Baldwin (2008:223) brings narrative and citizenship together, calling for a 'narrative citizenship that is given structural and organisational form'. In connecting narrative to the everyday social practices of citizenship, Baldwin (2005, 2008) refers to narrative as a way of being, constitutive of human existence, but focuses primarily on the stories we (try to) tell and that are told about us, consistent with his commitment to highlighting and countering the narrative dispossession of people with dementia. This thesis extends these important arguments by engaging more directly with the constitutive function of narrative in general, recognising its indispensability in empirical studies of ageing, and acknowledging and responding to the challenges that narrativity can

present in the specific context of dementia research. I summarise each contribution in turn below.

Ontological, epistemological and ethical functions of narrative

In general terms, I establish the importance of narrative through the study's articulation and exploration of its mediating role in configuring not only our understanding of human experience, but also in structuring existence itself. This extension is in itself significant, as perceived limitations of forms of knowledge that are dependent on narrative often concern the question of the relationship between human existence and narrative, between living and telling. Polarised distinctions are drawn between theorists who equate narrative with life (e.g. MacIntyre, 1985) and those who conceive of narrative primarily as a cognitive instrument for imposing meaningful order onto the disorder of human reality or experience (e.g. Mink, 1978; White, 1981). It is instructive to better understand the ontological assumptions underlying different approaches to narrative, as they provide 'the crucial impetus for different epistemological and ethical perspectives in the debate on narrative and human existence' (Meretoga, 2014: 89-90). Integral to this debate are tacit assumptions concerning what is counted as 'real' in general and the ontological status accorded to narrative interpretation of experience in particular.

Ricoeur's (1984, 1992) comprehensive narrative theorising, located in the phenomenological hermeneutic tradition, overcomes the impasse between the polarised views and disentangles the above ontological assumptions, as discussed in Chapter Four. In brief, starting with the narrative pre-figuration of everyday actions and practices, he depicts both human experience and narrative as phenomena constituted by interpretative activity, and interwoven with one another in a complex movement of dynamic reciprocal determination. His concept of triple *mimesis* sets out different levels of meaning-making and the ongoing intertwinement of personal, cultural and historical narratives. Ricoeur (1992) thus sees narrative as deeply rooted in life, but this does not mean that life should be equated with narrative. It is problematic to simply identify narrative and experience with each other as this undermines critical and ethical reflection on how cultural and historical narratives shape our (self-) understanding and regulate our being in the world. However, it is equally problematic to draw a sharp opposition between living and telling as this lowers the stakes and 'loses sight of the complex existential significance of narrative' (Meretoga, 2014:90-91).

Narrativity in later life

Building on this general position, I advance additional arguments in support of narrative in the specific context of ageing into old age by engaging with temporality. In particular, I highlight that hermeneutics rejects the idea of reality as a series of point-like experiences, not simply because experience is always culturally and historically mediated, but also on account of its fundamental temporality. Human existence is understood as a temporal process of interpretation which involves a constant intertwining or comingling of the past, present, and future in the here-and-now (Ricoeur, 1984). Human's wrestle with time and the time in question is not objective clock time, but human time. In Chapter Four, I summarise Ricoeur's (1984) argument that narrative is the means by which we make sense of the temporal nature of our existence. Narratives not only convey what it is to live in the world, but also what it means to live in time(s).

The meanings of time, time's passing and time's tenses shift as we age (Achenbaum, 2001). Older people also have a lifetime of experience to draw upon, 'biographically accrued capital' (Mader, 1996:43). The notion of 'lifetime' underscores the temporal nature of human existence in the sense that it is finite, and narrative is the means by which we try to make meaning and find unity in our lives as a whole (Ricoeur, 1992). This imperative may be stimulated by the anticipation of an ending (Carstensen, 1992; Frankl, 1986; Randall, 2008). Narrative studies appear to be indispensable for empirical research on ageing, as evidenced by the development of the specialist field of narrative gerontology. This field privileges narrative due to its capacity to facilitate engagement with fundamental aspects of the experience of ageing. The study calls particular attention to identity development in later life, life review, the risk of narrative foreclosure, the possibility of connecting with broader temporal horizons through generativity and shifts in the relative importance of knowledge-related and emotion-related goals. These insights are of value alongside the cultural dimensions of narrativity, indicating that the experience of later life and the anticipation of its ending may be halting, disruptive or redemptive.

Holding on to narrative in dementia research

In this thesis, I consider the importance of narratives in the specific context of dementia research, first by emphasising that dementia is only one aspect of experience and it is important not to lose sight of the broader and longer narrative; in Jim's words, '*there's more to me than this; people forget*'. I also develop arguments to establish the

continued place of narratives in this field by acknowledging and responding to the implications of the temporalising function of memory and the capacity to intend oneself into the future (Ricoeur, 2004). In developing the methodology for this study, I draw upon Ricoeur's (2004) phenomenological distinction between abstract, effortful recollections and more spontaneously evoked memories to increase possibilities for participation. I also utilise the different levels of meaning-making set out in Ricoeur's (1984) conceptualisation of triple *mimesis* to differentiate my own interpretative activity in the form of emplotment from the various events, happenings and associated meanings, as expressed and sense-checked by the participants. This approach respects, values and engages with their own situated meaning-making activities, without placing potentially unrealistic demands on participants to make connections between events or to remember what they discussed with me over a period of several months.

The people taking part in this study were able to recall, evoke and articulate memories and imagined futures within the flow of actions, but I also allude to the capacity of Ricoeur's theorising to sustain the narratives of people who can no longer do so and to embrace these narratives as vital forms of knowledge. Specifically, Ricoeur's (1992) attention to the co-authored nature of all narratives and to shared memories, particularly through the phenomenon of growing older together (Ricoeur 2004) introduces important support to a range of mechanisms seeking to sustain the narrative agency and identity of people as the detrimental effects of dementia increase. In addition, Ricoeur's (1984) concept of 'refiguration' lends philosophical moorings to the revelatory and transformative potential of the narratives of people with dementia, enriching Baldwin's (2008) account of monastic reading. Together these contributions strengthen the case for narrative as an important form of evidence, generally, for older people and people living with dementia through all its 'stages'. They enhance the concept of 'narrative citizenship' by making explicit the connections between narrative and the everyday practices of citizenship.

Extending the Research Agenda

The second aspect of the EXPECT framework argues for a broader vision and understanding of experiences of dementia that looks beyond the health and social care landscape where most research has been conducted. In so doing, the intention is not to detract from the importance of research that has the improvement of care quality as its goal, but rather to expand the research agenda to recognise people with dementia as

participants in ordinary social life and as equal citizens. I discuss the study's response to this appeal, first through its purposeful framing of the research questions to ask how an ordinary life is accomplished by older people living with dementia, then summarising the insights gained through the study's sustained attention to temporality.

Extending the research agenda into the realm of the ordinary

Through this study, I seek to contribute to the growing body of research dedicated to enabling older people with dementia to live positive lives as citizens. In conducting a review of the dementia literature, I was struck by persistent calls for ordinariness from older people judged to have crossed the ambiguous threshold of 'ordinary forgetting' (Lock, 2013). I was also struck by the force of the dementia label, becoming increasingly mindful of its pervasiveness as the review continued. In particular, I was alerted to the capacity of a biomedical diagnostic label not only to easily occlude the everyday lives and meanings of people so labelled, but also to shape research questions and influence the knowledge produced (Alsaker and Josephsson, 2011). The framing of identities within qualitative studies can either open up or close down possibilities for complex and radical self-representations (Fisher, 2012). Such observations resonate with Baldwin's (2008:25) discussion of the constraining force of 'stories in the wider world', whereby some voices are capable of framing the questions and setting the agendas, restricting the stories that can be heard. By focusing on 'older people living with dementia' in this study, I recognise that, inevitably, I am part of the labelling process. In view of this, I consider the careful framing of the research questions in a way that does not foreground dementia or presume difference a small but important step towards enhancing narrative citizenship.

In progressing the study, I attempt to bracket dementia for as long as possible, in essence putting dementia on the back burner as I enter the field. I try to engage with each participant in the context of his or her whole life rather than through the filter of the diagnostic label. In so doing, my intention is not to wish away impairment, but rather to enable each person to determine the place that dementia, or memory loss, occupies within his or her unfolding narrative and identity. I find strong support for this approach in the mounting challenge to the growth of the biomedicalisation of ageing and memory loss for philosophical (Hughes, 2013), epidemiological (Brayne, 2007), anthropological (Lock, 2013) and sociological (Beard, 2016) reasons. Since commencing the study, I have been further encouraged by recent arguments to extend

considerations of citizenship-as-practice into ordinary life within citizenship studies in general (Neveu, 2015) and within dementia studies in particular (Bartlett, 2016).

Extending the research agenda into the temporal realm

The study's engagement with temporality not only underscores the indispensability of narrative in studies of later life, but also illuminates the need to see the actions, events and people that comprise these narratives in time. As such, every event is perceived as happening not in some point-like instant, but rather through the dialectical thickening of a past and an implied future. Equally, people at any 'point' in time are in the process of becoming and they are historical beings retaining their previous experiences as part of themselves. This attention to the temporal nature of existence enables me to connect with shifting temporal horizons encountered in the field in response to the exigencies of different situations, to the spontaneous forging of connections between events separated by space and time, and to the unfolding nature of people's narratives and lives. Crucially, it adds an often overlooked third dimension to the people taking part in the study.

Past experiences manifest in the present as embedded habits, not only as bodily movements and acquired personal and cultural dispositions, but also as patterns of thought. They are also partially available through recollections and spontaneously evoked memories. By connecting with the habitual and recollected past and imagined futures, I develop a deeper understanding as to why the things the participants strive to be and do are important. I become more aware of the depth, complexity and thickness of their lives. I also observe that although things may get a little 'fuzzy' around 'the pivotal present', the participants' temporal horizons are broad, in some cases extending beyond their own childhoods to draw upon ancestral memories and often a more generative future is envisaged.

Additionally, sustained engagement over several months and thus through different seasons facilitates an understanding of the ongoing quality of everyday life. This includes attending to the ways in which disparate actions and events, enacted, recounted or imagined within time, and the in-between happenings that occur, are recalled or envisaged over time, are incorporated into the participants' narratives. There is also the chance to discover whether possibilities for participation, contribution and growth considered are actualised, constrained, denied, or discounted in the

imagination. I learn that the diagnosis of a dementia sub-type need not constitute *the* major disruption in life that participants are striving to make meaningful.

Following the EXPECT heuristic, I look more closely at the fruits of the Narrative Inquiry through a critical lens later in this chapter to ascertain what they add to the field of dementia research. First, I reflect upon the study design and conduct through a social citizenship lens, with particular emphasis on the possibility and actuality of participation, authenticity and mutual recognition.

Enhancing (Narrative) Citizenship by Facilitating Participation in the Study

Research that employs a social citizenship value lens demands new ways of conducting research with older people living with dementia that recognise their diversity, are attentive to power imbalances within relationships, facilitate meaningful participation and promote authentic human engagement (Bartlett and O'Connor, 2010). In this section, I consider the process of doing Narrative Inquiry, drawing upon the participatory dimension of the EXPECT framework. I first recap briefly on the level and nature of participation facilitated by the methodology, as discussed in Chapter Five and then assess the success of the participatory principles that informed the initial study design and guided its ongoing conduct.

Building in participatory principles from the start

Participatory research demands that attention to power and participation ground the entire research process (Bartlett and O'Connor, 2010:103). Within dementia studies generally, fostering genuine participation presents distinctive challenges; within the confines of this doctoral research study, participatory principles serve as a guiding but distant ideal. However, while recognising that participatory research is concerned with 'how' research is carried out rather than which data generation methods are used, thinking carefully about data creation can help promote a sense of citizenship (p104).

As detailed in Chapter Five, the study design aimed to ensure sufficient flexibility to respect the varied lifestyles, circumstances and distinctive attitudes to and ways of ageing for each person or couple taking part. I was keen to work responsively to participants' understandings of and abilities to engage in everyday 'activities' and their willingness to involve me in these activities in different social contexts. At a minimum, I hoped to give the participants some degree of control over the research process by fitting in with their daily lives and preferences. I had to stipulate the maximum number

and duration of meetings with each participant or couple so that the likely demands on their time were clear before they consented to take part, but within these limits the participants were able to choose where and when to meet with me, what we did together, for how long and how often. All participants report that engaging in activities as part of the study is a source of enjoyment.

Selecting methods to facilitate participation

To my knowledge, narrative-in-action has not previously been used with older people with dementia. However, I drew encouragement from other research studies exploring 'what older people with dementia do as they are doing it', typically through the use of methods combining participant observation with interviews or 'in-situ conversations' (e.g. Bamford and Bruce 2000; Boyle 2013; Phinney et al 2010; Ward and Campbell, 2013). Through these studies I anticipated that shifting the emphasis from telling to showing or enacting will reduce verbal communication demands. All participants in the current study were able to articulate their thoughts and feelings verbally, although this became more difficult for Jim as the study progressed. Jim's abilities to show and enact deteriorated in parallel with his speech and the anticipated benefits did not materialise. The previous studies also showed that engaging with situated activity increased opportunities for participation by reducing the need for recall and helping to foreground multi-sensory experiences. Emmel and Clark (2009) further observed that placing events and experiences in their spatial context helped participants to articulate their thoughts.

Within this Narrative Inquiry, I am able to add to the above understandings by engaging with Ricoeur's (2004) phenomenological *sketch* (italics in original) on memory. I find that in this study, rather than anchoring participants in the present, engaging with familiar surroundings and taking part in routine activities often prompted or even spontaneously evoked episodic autobiographical memories. The memory prompts varied from artefacts already purposefully distributed through Ann and John's home and the echoes of midnight games of hide-and-seek from their garden, through Tommy's retrieval of his mother's death certificate and Hector's digging out of travel memorabilia ahead of my visit. They include not unexpected encounters with Chrissie's mother's former headstone in her garden or the place on the golf course where Hector's friend Archie dropped like a stone, and the less direct associations with falling snow or the carvings in Roslyn chapel. All facilitate participation in meaningful ways.

Although not a central feature of this study, I am also able to observe the ways in which different types of memories (declarative and procedural) are variously recollected depending upon the prevailing circumstances, as illustrated by the following extract:

We leave the church café and go to catch the bus home. As we walk along the road, I remark that the numbers on the bus stop are hidden by the snow. Tommy tells me *'It could be like that every day for all they mean to me now'*. (Grace told me before we set off that we can catch the 24 or 86A, adding *'Tommy won't remember'*). I ask what he would do if I wasn't with him and he retorts, *'When were you last on a bus hen? They have drivers – you can ask'*. I think fair enough, but when the 24 bus pulls up Tommy says *'This'll do us'* and goes to get on. I ask how he knows that it's the right bus and he says *'My you're awf'y daft, it says up there'*, pointing to and reading out the name of the bus destination. I decide to dispense with the daft questions. Once on board, we are chatting about the scenery and I comment on how nice the bus route is. Tommy agrees and tells me *'It doesn't matter which bus you get from the church back home, but if you're going into the city you're better to get the 24, because the 86A goes all round the houses'*. [Field note, M1_01]

This extract highlights the contrast from Tommy declaring in the abstract that he had no idea what number of bus we could catch home, suggesting he would just ask the driver once standing at the bus stop, stepping forward when the bus arrived because he recognised the destination name and finally seamlessly threading the numbers of the two buses that ran past his front door within the flow of a relaxed conversation. While Sabat (2001) has highlighted that people's ability to recollect in artificial test situations can differ markedly from actual practice situations, the above example highlights variations *within* the situated practice of catching a bus, subject to levels of abstraction, temporal distance and the degree of relaxation. While I'm primarily interested in the implications for participation, this observation suggests possibilities for further study.

Discovering participatory possibilities together

When I enter the field, the participants play a significant part in shifting the shape of the research study. As described in Chapter Four, although attending to 'context' is always central to my research aims, I set out with an aspiration to locate the experience of living with dementia within a broader socio-political context. As I spend time with the participants, it soon became apparent that 'context' matters at two levels: the immediate contexts in and through which they enact their daily lives and the changing contexts that form the 'backdrop' of their biographies, framed by the guiding ideal of

the narrative unity of a life. This set me off on a journey down the long road that eventually brought me back to recognition (illustrated in Appendix XIV). The participants also sense check my research aims, for instance Chrissie decides to take part because she sees the value of the study, while others think carefully about the sorts of activities I should take part in with them to provide the best possible understanding of the challenges and joys of everyday life. I also process a substantial ethical amendment as soon as I realise that some participants wish to take part as a couple and am forced to reflect on the assumptions underpinning this oversight.

The participants are well aware of the evolving direction of the study. Just as I observe them, they observe me. They ask about my progress and provide helpful assessments. Ann and John's intellectual interests prove particularly useful in this respect. When John calls attention to the limitations of the 'little yellow leaflet' in conveying my evolving interests, an interesting discussion ensues. Ann is delighted by the change of direction, remarking that *'It's so much more interesting for us, and more useful I imagine'*. As mathematicians, they found the rejection of objectivity and the idea that a change in focus was to be expected intriguing. Ann states *'It's all rather organic, and more honest I think'*. She does not simply participate in the discussions, but asks decidedly tricky questions, *'What do you mean by activity?'* and invariably comes up with *'the apposite word'*. She also offers critical insights such as *'an awful lot of things in life just happen, luck plays a part too'*. In so doing, she drives a coach and horses through stereotypical representations of the 'Alzheimer's sufferer' and hierarchical awareness level models.

I conclude that while planning for participation is absolutely necessary, remaining open, alert and responsive to emergent opportunities is equally critical. While established ethical procedures do not necessarily lend themselves to the levels of responsiveness I desire, a degree of flexibility within the study design is tolerated by the Research Ethics Committee and when a strong rationale for change is put forward, I find it receives a favourable opinion.

The methodological attention to meaning-making in action also extends participant involvement to the initial stages of the narrative analysis. Although the emplotted narratives presented in Chapter Eight are my interpretations, the constituent parts, the events, happenings and associated meanings are co-constructed with the participants. Chrissie is very clear that participation in the study offers an opportunity to resist

reification and pursues recognition by representing the complexities of her life and identity; *'People need to know (the detail), it's what's made me who I am'*.

The study's flexibility also gives rise to different possibilities for me, as a researcher, to co-participate in aspects of everyday life as lived. For instance, seeing the maze of lockers in the swimming pool changing room through Chrissie's eyes proves particularly enlightening, and I am staggered when I realise just how many process steps are involved from leaving her house to entering the water to take part in an aquarobics class conducted with older people in mind. Equally, when I join Hector and his friends at the golf club I discover that he has a longstanding reputation for boastfulness, calling into question an interpretation of his recollected past achievements as compensatory mechanisms. This notion of co-participation highlights the mutual nature of the research, the importance of the mutual construction, ongoing negotiation and ultimately the ending of research relationships and the necessary interplay between participatory and ethical research principles and practices. I therefore look at the interconnections and potential tensions more closely.

Engaging with Ethical Dilemmas on the Narrative Inquiry Landscape

In Chapter Five, I considered the main 'desk based' ethical issues that I debated when designing the study. A social citizenship value lens also demands a more far-reaching assessment of the ethical issues underpinning research in the area of dementia (Bartlett and O'Connor, 2010). I therefore reflect upon my experience of entering and exiting the unfolding stories of the participants with care, and the many ethical dilemmas, potential role conflicts and moments of emotional compassion experienced during those in-between days on the Narrative Inquiry landscape. I do so in some detail because this process of reflection forces me to see afresh the limits of rational planning and the value of ongoing reflexivity. It also adds an invaluable experiential layer to my understanding of everyday life with dementia and the meaning of intersubjective recognition. This understanding, together with the critical appraisal of the narrative findings that follows, has important implications for how we relate to older people whose lives are affected by dementia.

I first engage in 'care full' deliberation (Barnes, 2012) about the research relationship by drawing on ethic of care principles, before setting out the ways in which the participants helped me to appreciate the research study as a mutual endeavour. I then discuss the various ethical issues encountered in the 'small moments of doing' (Stern,

2004) research and consider the concept of mutuality in the context of the sensitive management of ending the research relationship. I finally draw conclusions about the enactment of social citizenship values within research practices and the *doing of* (research) relationships.

Engaging in 'care full' deliberation about the research relationship

On entering the field, I am keen to conduct the study within relationships embodying principles of care ethics (Barnes, 2012; Tronto, 1993; Sevenhuijsen, 1998). The ethic of care framework positions 'care' as both a form of practice and a set of sensitising moral principles that can guide conduct within diverse contexts and relationships, and I consider them a useful starting point in helping me to pay attention to, try to understand and respond carefully to the particularities of uniquely constructed research relationships, which I anticipate will change and deepen over time.

Ward and Gahagan (2012) consider how an ethic of care framework, based on the interconnected principles of attentiveness, responsibility, competence, responsiveness and trust, can be applied to develop participatory research practice. Specifically, trust is identified as a condition for and outcome of careful research practice, developed iteratively throughout the study rather than established once and for all at the outset. Attentiveness applies to all involved in the research, the political context, methodologies and types of and access to knowledge. This includes understanding participant motivations for contributing to research and sensitivity to their previous experiences. Importantly, the authors highlight that it encompasses attentiveness to temporal dimensions of relationship building, including an appreciation of former relationships and setting a new path forward for those involved. Responsibility entails thinking through who needs to be consulted and involved in all stages of the research and the ensuing practicalities. Competence addresses the question of aptitude to do the research, which in my case requires, at a minimum, an initial understanding and experience of relating to an older person with dementia. Finally, responsiveness involves recounting experiences of data collection and ongoing sense-checking to care for all participants.

Worrying away at the edges

This elaboration of the ethic of care principles is useful in supporting me to think through my responsibilities as a researcher, which seem rather daunting, and underscores the need to bring the perspective of all participants to the fore. I

understand recognition as prerequisite to empowerment. A sense of equality is also particularly important in Narrative Inquiry, together with the mutual construction of the research relationship (Clandinin and Connelly, 2000). I am mindful from the outset that the study is not simply a matter of involving the participants in a set of research activities, rather I am asking them to allow me to co-participate in the activities that constitute their everyday lives. Barnes' (2012) elaboration of the principle of responsiveness to include detailed consideration of the place of reciprocity within relationships causes me to approach the question of power imbalance from both perspectives, and to acknowledge my own discomfort in asking so much of participants yet, beyond honouring this, being unable to offer much, if anything, by way of return.

There are some reciprocal acts embedded within the doing of everyday activity, for instance, helping Hector with domestic tasks and sorting through his travel memorabilia or assisting Chrissie to put the cushions on her sofa, but they seem very small when set against the generous giving of the participants. Acknowledging this discomfort is one thing, but I am unsure how to address it. I find myself worrying away at the edges of these disparities. I am also uncertain what this aspirational 'mutual construction' of the research relationship should 'look like' and how to shrug off my deeply ingrained assumptions based on an economy of exchange. The participants show me the way.

Coming to understand the study as a mutual endeavour

As described in Chapter Six, each research relationship is qualitatively different, dependent in part on the sorts of activities enacted and the types of experiences shared together. For instance, Ann and John cause me to engage with couplehood and Chrissie alerts me to the notion of 'corporeal generosity' (Diprose, 2002) through her openness to others. However, it is Tommy who first alerts me to the parallel processes that are taking place within each of the research relationships, albeit in different ways, underscoring the mutual nature of the research endeavour. It is also my relationship with Tommy that casts a practical light on process consent issues, presents the greatest number of ethical dilemmas and boundary conflicts, and that I become most anxious about ending. It is therefore this particular relationship that I reflect upon in order to give a sufficiently in-depth account of the issues encountered. Drawing on my field notes and reflexive logs, I call attention to the assumptions that I make, and illustrate the sorts of difficulties that can arise while doing research of this nature, expressed in practice by relational, emotional and embodied persons.

Mutual construction of the research relationship

"Good morning my sweet angel, aren't you a sight for sore eyes. The way you described yourself on the phone I was expecting some old crone". These are the first words that Tommy says to me when I arrive at his door for our introductory meeting. As I step inside, he bends down to continue winding up the cable of the Hoover he had been *'running around with'* in preparation for my visit. I realise that, much as I had set the expectation that I was a rather more 'mature' student, in case he anticipated someone much younger, Tommy had also engaged in managing my expectations, having told me on the phone that physically he was still quite fit for a man of his years. I am struck by the parallels. Also, just as I had wanted to strike the right note, arriving bang on time to demonstrate that I was a punctual, reliable woman, he too wanted to show me that he was not only a fit man, but a responsible and modern man to boot, unashamedly contributing to domestic life.

The similarities do not end there. I had thought very carefully about what to wear, appreciating that participants often adjust their responses depending on the researcher's clothing and appearance (Mishler, 1996). I did not want to appear too formal, stuffy or overly professional, but also didn't want to look too casual or, heaven forbid, like mutton dressed as lamb. I smile when Grace reveals that Tommy had decided to wear his *'new Christmas jumper and good cords'*.

There are further equivalences. I am attentive to Tommy and Grace's motives for contacting me and agreeing to take part in the study, and they are attentive to mine. They assume responsibility to meet my needs as a researcher and do so competently, coming up with the mix of mundane and more special activities exactly as set out in 'the wee yellow leaflet'. As I spend time preparing for each visit, Tommy, with Grace's help, is busy digging out materials he thinks might be useful to me, such as the birth certificate confirming his illegitimacy, his mother's death certificate dated two years later and a handful of photographs testifying to the poverty of his youth.

Responsiveness is also a two-way affair, and my transcripts and field notes reveal that we constantly check things out with each other – *How is this going for you? Are you still happy to be involved? I'm glad it's useful to you hen, but what are your professors saying about it? Are 'we' doing alright?*

Synergies are not confined to the conduct of the research, but are evident in the mutual construction of our relationship more broadly. I try throughout to tune into Tommy's

mood, purposefully avoiding probing for details of various mishaps and things he'd '*gotten wrong again*' whenever I sense that he doesn't want to dwell on them. This tuning in is also reciprocal. We take turns. On one occasion when I have been burning the midnight oil, battling with philosophical texts, Tommy tells me '*You're looking awfy tired hen*'. He then asks '*Is it this study, or is there something else*'? When I reply that I have probably bitten off more than I can chew with some of my reading material, he advises, '*We can only do our best*', underscoring that the study is a joint endeavour, reminding me gently that I need to conserve my energy levels for the field work, and restoring a much-needed sense of perspective.

Another day, while we are on our way to visit the chapel, I note that Tommy seems very subdued after telling me that Grace is becoming '*his minder*'. I am aware that I am trying, and having some success, in cheering him up and conclude that, ethically, this is acceptable. Once inside, at one point I step back to look up at a carving of the seven deadly sins. There is a steep stairwell leading to the crypt just a few feet behind me. Tommy warns me '*mind you dinnae step too far back, or you'll be down that stair*' and I thank him, adding '*looks like you're my minder today*'. I had actually forgotten about the stairs and although I am a safe distance from them, I'm touched that Tommy is looking out for me. Glancing up at the carving he jibes '*pride comes before a fall*' and we laugh, equally delighted by his quick-witted remark.

Ethical issues encountered in the small moments of doing

I experience many ethical dilemmas over the course of the study. While some are addressed at least in part through anticipatory planning before entering the field or ahead of a given meeting, most issues are thrown up in the midst of doing the research and require more spontaneous responses. The main issues take the form of determining how to adhere to research protocols without compromising authentic engagement, enacting responsibility and deciding whether to observe or intervene in the flow of action. They also include the development of intense relationships and the implications for blurring the boundaries between care and protection, altering the future course of events, managing boundaries and role conflicts and attending to the emotional self. I consider each in turn.

Adhering to protocols, engaging authentically

As Bartlett and O'Connor (2010) highlight, much of the discussion about the ethical conduct of dementia research has been concerned with informed consent issues, although even within this sphere further work is required to ensure a sufficiently

sophisticated approach capable of facilitating citizenship and providing the necessary protection. The importance of process consent (Dewing, 2002) within dementia studies is now widely recognised, but in practice I experience uncertainty as to how to implement this appropriately for each person without appearing patronising. I worry about how to strike the right balance, only to discover that Tommy will point out if I am rather laying things on with a trowel. For instance, when I ask somewhat clumsily at the start of one of our meetings, *'So Tommy, before we set off, can I just check that you are still happy to be involved the study'*, he cuts me off stating *'Well I wouldnae be here if I wasnae'*. Good point, but I am aware of various mix-ups in Tommy's day to day life and the potential for misunderstanding is real. I realise that I need to find a means of checking things out within the natural flow of conversation. Tommy refers to my audio recorder as my *'wee James Bond gadget'* and taking his lead, together we find more informal ways of ensuring that he understands that I will be recording and reporting on specific conversations and observations, often by bringing 'James Bond' into the mix.

Determining whether to observe or intervene in the flow of actions

The narrative-in-action methodology stresses that, as a researcher, I must try to enter the person's way of living, talking, and acting in an open-minded fashion, and at the same time must carefully consider each response to avoid bringing in topics from outside the actual ongoing activity (Alsaker et al, 2009). There is therefore a tentative quality in these situated communications at times, in that I am aware that the emergent storylines could develop in another way if I respond differently. While mostly I am able to refrain from introducing topics of interest to me, the same does not hold for the requirement to alternate between actively refraining from intervention and being passively led through the stream of actions (Lawlor and Mattingly, 2001). On several occasions, I am uncertain whether to observe this stream of actions or intervene.

For instance, on one of our outings, just as Tommy is ordering his 'soup and roll combo', a small sign stating 'no card transactions under £5' catches my eye. The combo costs £4.20. Before my first outing with Tommy, Grace was insistent that Tommy pay his own way for everything, mindful of my student status. I agreed, also thinking, very much as a researcher, that it would be useful to see how Tommy manages different payment transactions and the associated interactions. As a result, I know that Tommy can no longer manage cash transactions and does not carry cash, but can use his bank card and remembers his pin number. I find myself asking Tommy if he is going to order a coffee too, but he replies *'just the soup hen'*. I then frantically start trying to 'fix things' in my

head, something I have spent the latter part of my working life encouraging others not to do! Activity switches from execution to narrative rehearsal (Ricoeur, 1984) in my imagination.

I run through different options. Should I offer to pay on this one occasion? Should I suggest Tommy pays for both lunches and later give Grace the cash for mine? Or should I do what the methodology advocates and 'follow the flow'. Should, should, should, I am not *supposed* to intervene in the course of action, but does this amount to standing back and watching Tommy walk into difficulty and perhaps looking 'foolish'? In the moment, I am unsure whether to observe or intervene. I find myself juggling these different requirements. Through my indecision, I observe by default.

When Tommy comes to pay, sure enough the woman at the till points to the notice and apologises for being unable to accept a card payment. Tommy seems nonplussed. He looks back at the various items on display, indicates he'll take a piece of the millionaire's shortbread, picks up a handful of napkins, turns to me and says '*I'll take that back and split it with Grace*'. Sorted! I am taken aback by my lack of faith in Tommy's ability to handle the situation and by the strength of my desire to jump in and rescue him. On reflection, I realise that I did not do what I would usually do outside of the research field, namely point out the sign to him and ask what he wanted to do. In my bid to be a 'good' researcher, I drop the authenticity ball. My indecisiveness however is in part the result of a deepening knowledge of Tommy's situation, the developing intensity of our relationship and a growing desire to protect him.

Developing intense relationships, blurring the boundaries between care and protection
Consistent with previous research with people with dementia (Clarke and Keady, 2002) on the whole I find prolonged engagement conducive to establishing a productive and ethical research relationship. However, the extended period of engagement also raises some issues, particularly as relationships deepen. As with the hermeneutic circle, knowing more of Tommy's whole story enriches my understanding of the parts, and knowing the detail of the parts adds to my understanding of the whole. As the study progresses I make connections between Tommy's accounts of '*being put in with useless lot at school*' and his fresh concerns about '*looking like an old fool*'. My heightened awareness of the depth of his anxieties brings with it an intensity in my own emotions; I become anxious for him. My instinct (as a woman) to protect Tommy from situations where he might end up looking 'foolish', at least in his eyes, at times conflicts with the imperative (as a researcher) not to intervene. In practice, I find the distinction between

'care' (particularly responding to another's need for emotional security) and 'protection' (especially acting with the intention of preventing another from emotional harm) a bit blurry. Alongside concerns as to whether to act or observe the flow of action, there are times when I am unsure how to respond where I appreciate that this could potentially influence the future course of events.

Developing intense relationships without altering the future course of events

Lawlor and Mattingly (2001) highlight the struggle inherent in simultaneously developing intense relationships as part of the research commitment and minimising the intrusion on and alteration of the everyday life experiences of interest. I experience these struggles on several occasions. For example, as we work our way through a numerical key on a visitor's map, Tommy is prompted to tell me about something that happened at the men's group that he attends. I struggle to follow his account, but gather that he became very anxious when asked to remember the number 14, I think as part of a group exercise, but later felt more confident when he managed to blurt out '14' at the appropriate time. When he concludes, he looks rather pleased with himself. I don't know what the exercise entailed, but in that moment, I reckon that this doesn't matter and the key things to focus on are Tommy's emotions – 'getting hot under the collar' and then feeling 'more confident'. I don't want to undermine his sense of satisfaction by letting him know that I haven't understood what he's pleased about. I tell him *'That was great Tommy, you know, that you managed to do that, but when you say you were getting hot under the collar, what were you worried about?'* Tommy tells me, as if stating the obvious, *'looking stupid'*, There it is again – this fear of his. I go on to say, *'so, remembering your number, that made you feel more confident that....?'* and Tommy replies *'I can keep going back'*. So, there we have it.

How should a researcher respond in a situation like this? I find myself saying *'I know how much you enjoy the group and from some of the laughs you've told me about, I bet the other men really enjoy your company too – whether you remember the number 14 or not'*. As soon as I say these words, I realise I could be in danger of crossing a line because 'I' am invested in Tommy and don't want him to stop going to a club that he enjoys and perhaps holds deeper meanings for him. So far, he's coming up with his own solutions. So far. What's the 'right' thing to do? I could point out all the things that he can do. Or that Steve, the organiser, sounds nice and might be willing to help him out. I'm not sure what's appropriate, so I decide to pull back and just leave him with the seed of thought that his company is enjoyable and not dependent on his memory.

I revisit Ward and Gahagan's (2012) application of the ethic of care principles, notably attentiveness to the temporal dimensions of relationships and setting a new path forward. Bartlett and O'Connor (2010) also argue that research participation can provide a site where people find support for identities, meanings and self-worth. While mindful that this is a Narrative Inquiry and not an intervention study, I conclude that it is ethical, and consistent with the empowering ethos of participatory research to call attention to a research participant's capabilities. Nevertheless, I worry about potential role conflicts.

Developing intense relationships, managing boundaries and role conflicts

It is expected that researchers negotiate multiple roles, such as data collector and empathetic listener (Lavis, 2010). Ethical dilemmas about possible role conflicts concern what constitutes an appropriate distance between participant and inquirer. As Lawlor and Mattingly (2001) emphasise, developing intense relationships is an important part of the research commitment in studies of this type. I come to see that my relationship with Tommy is, in itself, increasing my understanding of everyday life with dementia. It is an invaluable research instrument. For instance, on one occasion I am standing at the bus stop waiting for Tommy, watching the 'bus due' clock count down. When the bus turns the corner, I can see that Tommy is at the front of the queue of people waiting to get off, smiling and joking with the driver in his own inimitable way. I find myself smiling too and realise that I am genuinely pleased to see him. I salute when he sees me as he steps off the bus. He walks towards me and grabs the fur of my jacket collar, saying '*Are you still not feeding that cat*'. I laugh, struck and also delighted that he has remembered my coat and his previous joke about it. I realise in that moment how much we value such social niceties and how difficult it must be for someone to build new relationships when the ability to lay down fresh memories is impaired. Yet my genuine pleasure in seeing Tommy also raises the important question of boundary management.

I am mindful that I have entered Tommy's life as a social researcher and not as a befriender. I understand that developing and maintaining healthy boundaries around researcher roles is critical for conducting research in this field, given the potential for role confusion that may result when involving people with dementia (Nygård, 2006). Consistent with understandings of research relationships as mutually constructed, Brinkmann (2007) stresses that boundary confusion is a bidirectional process whereby misunderstandings from either the researchers or participants can result in

inappropriate roles. I wonder if our boundaries are unhealthy, if the roles being enacted are inappropriate. Kvale (1996) in particular warns about the dangers of researchers masquerading as friends, thereby masking the power exertion in so-called caring consensual dialogues, but I don't feel my relationship with Tommy is a masquerade. Perhaps I have misunderstood.

Developing intense relationships, attending to the emotional self

I start to wonder if I have come to care too much. For example, I am deeply moved when Tommy tells me about Grace sitting in tears watching the dementia storyline unfold on Emmerdale and not knowing what to say to her. And I am shaken by news of his (as it transpires futile) plans to recover the ability to write his signature when he discovers that this form of identity expression has been lost. I recognise the limits of my competence; I am a researcher, not a therapist. I have become the repository for his emotions and feelings and I know that it falls me to hear and hold his stories. I acknowledge the enormity of the issues that Tommy is wrestling with and ask if he would find it helpful to speak with someone skilled in providing emotional support, but he tells me no, there's no point worrying about something you can't change and that he just takes things '*one day at a time*'. Later, when he goes to buy his book and engages in banter with the man at the cash desk, oblivious that he is creating a queue, I find myself welling up. I simply can't bear the thought of Tommy's jocular disposition getting lost along with his signature. I fear that I have become too involved, I have been negligent and allowed the boundaries to evaporate, like Mr Costello's disappearing ink.

At this point I find it helpful to read a special issue of *Qualitative Inquiry: Exploring Narrative Inquiry Practices* (2007, 13 (4)) comprising four articles in which narrative inquirers (Connolly and Reilly, Campesino, Downe and Mahoney) question whether they have acted appropriately given their degree of emotional investment and the intimate nature of the relationships established with their participants. Specifically, the authors are 'haunted' by notions of clinical distance and objectivity, as mandated by the quantitative paradigm (Connolly, 2007:453). Cognitively, they understand the differences between the two research paradigms, but still wonder if their feelings are legitimate and appropriate, even within the qualitative paradigm. The authors conclude that in research where knowledge is co-created and stories are co-authored, a stretching of roles is necessary. I recognise that dementia brings added complexity into the mix, but complexity does not equal rigidity and it does not eradicate the importance of attending to the emotional self of either participant or researcher.

Mutuality and the management of endings

Given my emotional investment in Tommy, it is perhaps unsurprising that I experience difficulty when this research relationship comes to an end. The management of endings is an issue that the Research Ethics Committee rightly grilled me on. I managed to address all concerns satisfactorily and indeed, drawing on my past experiences, was confident that I could manage endings sensitively. I knew from the outset that entering a relationship such as this requires some planning about how to end it (Lawlor and Mattingly, 2001). I also found ways to revisit the maximum length of involvement in the study repeatedly through the ongoing practice of process consent. Plus, I created a visit record sheet (Appendix XV) to offset the risk of misunderstanding, a bold visual reminder with its big, unambiguous finish line. What was I thinking? In practice, it isn't quite so straightforward. Below I consider the events running up to my wrap-up meeting with Tommy and Grace, and the way in which this meeting actually unfolds, before drawing conclusions through a social citizenship lens.

The end of the line?

When I meet with Tommy for the last time before our wrap-up meeting he asks me *'So have I filled up another few pages of that book of yours?'* I say, *'You most certainly have'* and thank him. He then says *'there's plenty more flower'*. I recognise this as a natural opportunity to once again revisit the study terms. When I then ask if he's willing to meet with me one last time to go through it all, and to thank him and Grace, Tommy replies that he's *'happy to keep meeting for as long as it's useful to me'* and adds *'you best speak to the secretary'*. I confirm that I will. He then says, not for the first time, *'It's fair given me a boost, I'm right glad I've met you, I tell you. Right glad.'*

There has been such a marked shift in Tommy lately. He is talking to me, opening up about his feelings and his fears. He seems keen to continue and I am captivated by his story. I wonder if we might extend Tommy's involvement in the study and take this issue to supervision, trying to drop the idea in casually. My supervisors are of course wise to me and when they ask about my rationale I realise that it is half-baked at best. My argument that there are important changes afoot in Tommy's life is swiftly countered. I know deep down that life goes on, there will always be changes afoot and Tommy's story will continue to unfold beyond the study. I recognise this same unfolding is happening with the other participants, who I also care deeply about, yet I am not facing the same dilemma. What's different about Tommy? I am not sure. I am

encouraged to have a conversation with a researcher who experienced something similar during her doctoral research study.

In the interim, I think hard about the situation. I am acutely aware of Tommy's lifelong need to make himself useful and frequent references to being '*put in with the useless lot*'. I have witnessed first-hand his delight on being described as '*a student*', and heard him chuckle when telling me about the lady at his church discovering that he *really was* doing some work with the University. Participating in the study means a lot to him, has in itself become a valued activity. Is the issue simply that I don't want Tommy to think that he is no longer *useful*? That's certainly part of it, but this is something that I am confident that I can handle sensitively. I recognise that it isn't simply a case that there are changes afoot in Tommy's life, I think participating in the research may have triggered a change in Tommy and I feel a sense of *responsibility*. Although I understand that this is something that needs to be appropriately managed, when I then think about the rationale for extending Tommy's involvement in the study from a purely academic perspective I conclude that there isn't one. Yet I am still keen to speak to the other researcher, hoping I might have missed something.

When I speak with the researcher, she listens carefully to me and I find it helpful to say things out loud. I discover that she had experienced something remarkably similar, with one of her participants beginning to talk about Alzheimer's towards the end of the study period, a word this participant had never used until that point. The researcher had reached the same conclusion, namely that this development must be addressed sensitively, but ethically did not constitute grounds to extend the period of involvement in the study. I take comfort knowing that I am not the only person to have wrestled with such issues and that the change I've noticed in Tommy is by no means exceptional, and arguably represents a positive development.

I telephone Grace, as is customary, to make the arrangements for the wrap-up meeting. Tommy has previously told me about a trip he'd made with his men's group to an underground cove in the nearest city. I'd expressed interest in it and Grace informs me that Tommy is keen to go there with me immediately ahead of the wrap-up meeting. It involves wearing a hard hat and scurrying about underground with torches, so it is not an activity that Grace has any appetite for, but she is very supportive of Tommy's idea. We arrange for Tommy and me to do this together and then meet up with Grace in a nearby café to enable me to thank them both and to reflect on the research. I am keen

for both Tommy and Grace to be present to avoid any ambiguity, and to make sure they are aware of sources of support should Tommy wish to talk more about his developing feelings. I am also keen to ascertain if both Grace and Tommy will be happy for me to keep in contact with them.

It takes two

When we meet up, it transpires that Grace has arranged for a private tour. I am still a bit apprehensive about wrapping things up in case Tommy is disappointed, but soon find that Tommy is actively managing the ending. Previously he has found all manner of ways of accounting for my presence; I have been introduced as a younger model that he's traded the wife in for, a lassie helping him out with a photography project, and perhaps most improbably, his wee sister. On this final meeting, he informs the girl hosting the tour that he has Alzheimer's and that he has been helping me out with some research, adding *'but that's coming to an end now and we've, well I'm hope I'm not being too familiar here, but I like to think we've become friends'*. I'm overwhelmed by his openness and courage, grasping the significance of this introduction instantly and reply that I like to think so too.

As we make our way into the darkness, I begin to question the wisdom of this choice of venue, experiencing 'felt' difficulty. The ground is uneven and we can only see as far as ahead as our torches allow. I am afraid that Tommy might fall. I spontaneously recall the helpers at Jim's stroke club, the memory serving pragmatic and semantic functions, acting as my guide (Ricoeur, 2004). Tommy, having been here before, seems more certain of the terrain and is delighting in the experience, one step ahead of me.

I relax a little and begin to enjoy hearing about the history of the place. When the guide tells us a story about people being thrown down a well and left to drown on account of their left-handedness, Tommy nods knowingly at me, saying *'that'd be me and you, if not for those nuns'*. I am aware that Tommy is left-handed, but am astonished that he has remembered me telling him that I too was left-handed as a child, but was forced to switch to my right hand at school. His memory is failing, laying down fresh memories is tricky and yet he has found space for this seemingly insignificant detail of my life, a detail I revealed to him some six months previously and that only a handful of people know. Standing there in our hard hats, torches in hand, my thoughts are flooded with an image of Merleau-Ponty's well. Our torch lights may only have penetrated so far into the darkness beneath, but we have looked at the reflections together, both struck by the

persistence and energy of traces from those formative years, jostling their way to the front and breaking the surface, despite having the greatest distance to travel. I think this may be a moment of mutual recognition. With another layer added to my understanding, I conclude that Tommy's choice of venue is wiser than I'd first thought.

Tommy chats to the tour guide, on several occasions getting lost in his remembrances, turning to me and saying '*You know my history*', '*you know my story*'. He expects me and trusts me to fill in the blanks, which I am able and happy to do. In so doing, he signals that his involvement in the study is over, our relationship has already changed. Once again, he is one step ahead of me. I am forced to admit that, despite my best intentions, I have seriously underestimated Tommy.

When we meet up with Grace later, she is quick to tell me that there have been positive changes in Tommy of late, and she thinks taking part in the study has been beneficial for both of them. Tommy agrees. Grace takes the initiative and tells me that she hopes that I will keep in touch and will always be very welcome to come and see them. I realise that the mutual construction of the research relationship continues until its conclusion. As Clandinin and Connelly (2000) suggest, whatever distance happens to be at work within the Narrative Inquiry is co-constructed by the participants and the inquirer. Far from being a passive research subject, at several points in the study, and certainly the most critical points, it is Tommy, with Grace's gentle guidance, who takes the lead.

Social citizenship, ethical participation and reciprocal recognition

Spending time on the Narrative Inquiry landscape puts me in contact with issues that arise in the moment. I see the limitations of rational planning, which tries to erode the vulnerable, emotional self. Holding on to the ideals of equality and mutuality, yet not wishing away cognitive impairment and enacting my responsibilities as a researcher is challenging at times. Behar (1996:6) suggests that all too often researchers and observers rely on methods to 'drain anxiety from situations in which we feel . . . helpless to release another from suffering, or at a loss as to whether to act or observe'. Methods cannot drain the anxiety from some of the situations I encounter. I begin to appreciate the necessity of ongoing reflexivity as I live the tensions so familiar to care workers and family members who inhabit the contested territories of everyday life (Clarke et al, 2010).

The experience of being in relationships, of *doing* relationships, adds an invaluable layer to my understanding. In the midst of doing, I experience uncertainty and feel compelled to act in different ways. I care deeply and understand the legitimacy and appropriateness of my feelings. I see that things can be very messy indeed, resolved by ‘muddling through’ in a particular context (Barnes and Brannelly, 2008:385). Most tellingly, I find myself worrying about decisions that are not mine alone to make. At a minimum, doing relationship takes two. Turn taking is permissible and it’s okay for the other person to lead the way. I come to see, to actually *experience* that we achieve best ends through the suspension of assumptions and through narrative and other communicative approaches grounded in deep knowledge of the particular, rather than an over-reliance on principles (Holstein et al, 2010).

Applying a Critical Lens

Having reflected upon the participatory and ethical dimensions of conducting the study, I now look at the fruits of the Narrative Inquiry through a critical lens. This dimension of the EXPECT framework returns to the rationale for broadening the dementia debate, discussed in Chapter Three. It underscores the need for studies which challenge the assumed homogeneity of people living with dementia and consider the influence of multiple sources of privilege and disadvantage on their everyday experiences, address the societal attitudes and barriers that people face and reflect the ways in which people living with dementia are participating in and contributing to society (Bartlett and O’Connor, 2010:7). I review the study’s response to these needs below.

Recognising diversity and the complexity of identity

Hulko (2004; 2009) has highlighted the dominance of more articulate and multiply privileged voices within dementia research. At the outset of this study, I sought to involve people with diverse social locations and characteristics and this aspiration was thoughtfully supported by the GP acting as Participant Identification Centre. However, once I got to know the participants as people, categories fragmented (Clandinin and Connelly, 2000:141). In conducting the research, I respond to the need to recognise diversity in a distinctive way.

Fisher (2012) also expresses concerns about the limitations of defining a person according to membership of a single group, such as ‘a person with dementia’, as this denies the complexity of human identity. She warns of the danger of constructing the identities of socially marginalised people as necessarily embedded in forms of

suffering, adding that qualitative studies should seek to reveal rather than erase the complexities of identity and recognise that social suffering may prompt radical forms of resistance. Following her arguments, I recognised the potential of the study to address forms of suffering caused when a person is objectified according to categorisations that are imposed externally (what they are) and to enable them to articulate alternative and more complex self-representations (who they are) (Fisher, 2012).

The people who took part in the study are of a similar age (ranging from 78-85 years) and thus all members of that 'last great generation' who spent their formative years living through World War II. Each participant is white. They all live within a two-mile radius in the same small Scottish town. Each participant has lived in his or her respective family home for over 35 years and can thus be said to be ageing in place. They are all well supported. Yet their biographies, current physical capabilities and life circumstances, attitudes to ageing, reactions to the diagnosis of AD or related dementia and ways of living with it are very different. Often such differences get lost behind the dementia label or overly attributed to social locations. Rather than representing storied lives as exemplars of formal categories, Narrative Inquiry enables the nuances and complexities of different experiences to be preserved (Clandinin and Connelly, 2000).

The resultant narratives are configured in ways that reflect the part that 'dementia' does or does not play in each person or couple's life and preserve other differences. The resources the participants call upon in making meaning of and living everyday life are diverse, with influences scattered throughout the life course, notably the incidence of previous disruptive life events. The structural forces of class (in terms of education and economic status) and gender cannot be ignored. Factors encompass more specific educational opportunities and choices, plus employment decisions made or enforced. Other influences include the presence or absence of strong parental or gendered role models, whether traditional male: female roles have been enacted within the family and the extent to which gendered assumptions are valued or resisted. The differences are manifest in the dynamic and dialogic configuration of complex identities.

Alongside differences in physical health and attitudes to ageing generally, there are important biographical differences. Couple-specific ways of relating differed and Chrissie did not have a long-term partner. The number of children, grandchildren and the existence of great-grandchildren shape occupational possibilities and necessities, but family relationships, dynamics, closeness of family in the sense of geographical

proximity and the competing commitments of family members have greater bearing. Loss or survival of peers, and loss or survival of friendships are significant, as are relationships with neighbours and community connections. Sustaining sporting and leisurely pursuits engaged in over the life course, learning or continuing to drive, buying a house near a bus route and making regular use of public transport all play a part in facilitating ongoing participation in and contribution to everyday life.

Societal barriers

A social citizenship value lens also looks beyond the individual and forms of capital to consider societal attitudes and barriers. The narratives call attention to ways in which the pace, intellectual and technological demands, capitalist priorities, ageist biases, environmental designs and reductive practices of twenty-first century life make things more difficult than they need to be. The fear associated with dementia was acknowledged by Tommy and the term dementia itself was problematic for Hector, but it would be too simplistic to attribute this fear solely to cultural representations. Despite the push for earlier diagnosis, there is a tendency to conflate AD with the end stage and most participants had direct experiences of people with advanced dementia. Hector in particular found this distressing, although perhaps less traumatic than witnessing the sudden death of his closest friend. Chrissie's brother had AD and was 'really bad at the end', but she explicitly positions this as preferable to sudden death. Chrissie is also the only participant who explicitly refers to the attitudes and responses of other people, as illustrated by the woman at the leisure centre who treated her as though she was 'not the full shilling'.

Recognising contribution and attending to misrecognition

A citizenship approach needs to be based on reciprocity so that the focus is not just on the resources required by someone, but also includes consideration of someone's strengths and assets (Marshall and Tibbs, 2006) and promotes participation and contribution (Bartlett and O'Connor, 2010). The narratives presented in this study illustrate what older people living with dementia can be and do. They assume responsibilities in line with many and varied life priorities and retained capabilities. There are diverse ways of practising citizenship, and those that foreground individualist assumptions are hard to sustain. However, many practices are relational, creative and generative. This depiction in itself counters cultural representations that valorise independence and catastrophise dementia.

The narratives also articulate how meanings are made in different situations and depict other diverse implicit or purposeful ways of resisting negative cultural narratives, including the barely discernible resistances found in the ordinary doings of ordinary people in the mundane places of daily sociability (Neveu, 2015) and in the private sphere (Fisher, 2008). The narratives affirm that people do not have to integrate a diagnosis into their identity to accomplish an ordinary, everyday life or to maintain the aim of living a good life, and partners do not have to respond to a diagnosis in the same way to live 'well'. The narratives lend support to my argument that different ways of responding to and living with dementia require equal consideration and the suspension of assumptions.

The study also calls attention to the importance of 'recognition' within inclusive and relational understandings of citizenship-as-practice. It illustrates that the quest of older people living with dementia to construct positive understandings of the value of their lives can be impeded not only by forms of misrecognition which position them as inferior (less competent and therefore not equal) and vulnerable to patterns of disrespect, but also those which fail to recognise their particularities and contributions and thus undermine their self-esteem. One particular form of misrecognition is the cognitive testing process. Specifically, it is not simply the ascription of the impaired label that proves problematic, but rather the process itself that participants find reductive and demeaning.

The study also considered how practices of everyday life are enacted in local cultures, which have their own history, rules and constitutions, making evaluation possible. People with memory loss are aware of these evaluations, positive or negative. The rules and expectations of different practices and cultures can be more or less accommodating and can open up or close down possibilities for being themselves, rather than defined by their age or diagnosis. The narratives offer examples of how the participants variously communicated their uncertainty regarding being able to continue to participate in and contribute to ordinary social life in ways that they found meaningful, and that were also socially valued. This uncertainty pertained to both processes of bodily ageing and concerns about being good enough citizens. As such, the narratives represent ongoing struggles for recognition. They add to the 'nascent field of academic narratives of resistance' (Beard, 2016:232).

Translating the Research into Practice

Having reviewed the theoretical, methodological and empirical contributions of the study, the final dimension of the EXPECT framework concerns the translation of the research outputs into practice. In so doing, I contextualise the narrative outputs within the key insights distilled from the review of the literature in Chapters Two and Three to consider the potential societal implications.

Unlike other forms of qualitative research where transferability of ‘thematic findings’ to other contexts is a key consideration, the value of narratives depends on their capacity to provide the reader with insight and understanding about the human condition. This is an important response to the urgent need to bring humanity back into considerations of ageing and dementia, as highlighted in Chapter Two. It relates directly to Ricoeur’s (1984) concept of ‘refiguration’ and the potential for revelation of what has previously remained unseen and unheard in the realm of the ordinary and for transformation, through an invitation to act differently.

The narratives recognise chance and vulnerability as inherent structures in our lives and preserve the blend of love and loss, joy and sadness, acting and suffering that characterise all human lives. As a set, they represent struggles for and the attainment of recognition and offer an account of the ‘ordinary doing’ of everyday life with dementia that is hopeful without being naïve. The narratives may be of value to different audiences, including people with dementia and their families, GPs, care professionals, students and dementia researchers. Specific narratives may be of interest to leisure centres, community centres and service industries.

Additionally, the contrast between the favourable enviroing conditions of the golf club, grounded in intergenerational and sustainable aspirations, and the more hostile and less accommodating environments afforded by the specific provisions of the aquarobics class and stroke club may also be of interest to those tasked with the development of ‘dementia-friendly’ communities. Taking a broader approach is consistent with Whitehouse’s (2013) calls for intergenerational initiatives and Barnes’ (2012) argument that we need to find ways in which we can all live well together.

From a policy perspective, in the short-term, there are signs of small and undoubtedly hard-fought shifts in thinking. In Scotland, the most recent Dementia Strategy (Scottish Government, 2017) acknowledges that diagnosis is not without issue, although early diagnosis is still championed. It also accepts that most people diagnosed are

considerably older than previously thought, often have other health conditions and established relationships with care professionals. While there are calls for 'more person-centred' approaches, dementia-specific provisions are still foregrounded. There remains an implicit assumption that diagnosis constitutes the major disruption in the person's life and integration of the diagnosis into identity is prerequisite to the ongoing accomplishment of a good life. The narratives in this study reaffirm that existing models of support can be very helpful, but challenge the assumption that what works for some should be regarded as important to all.

While recent policy developments offer some hope that the political push for proactive diagnosis is easing, in the interim the study lends support to assertions that diagnostic and ongoing cognitive testing could be kinder (Beard, 2016; Sabat, 2001; Smith, 2009). Diagnosis is a social practice and the potential for biographical and ethical fallout (Katz, 2017) should be more readily acknowledged.

Perhaps most significantly, the literature review in Chapter Two indicates that 'ordinary doing' or 'everyday activity' looks set to become the subject of increased attention across a range of disciplines with an interest in dementia in the future. The Narrative Inquiry may be of value for policy and practice, providing insights into how seemingly mundane activities contribute to meaningful existence and self-understanding, both within the flow of actions and overtime. These insights should be foregrounded when conducting 'some sort of functional assessment of capacity to benefit' (Brayne (2010) in conversation with Lock, 2013:233-234).

'Activity' is a loaded term, and the study illustrates the very different meanings and possibilities it holds for older people living with dementia, and the different routes to wellbeing that older people take. Older people with dementia have diverse capabilities, and when people are able to 'do' less, it is important not to lose sight of the importance of ways of 'being' and their generative capacity, such as those modelled by Ann. Moreover, older people with dementia may not recognise the important contributions that they continue to make to the lives of others. By being attentive to and appreciating more relational and generative forms of contribution, there is potential to respond to the human need for recognition and enhance self-esteem.

Alongside the emplotted narratives, my reflections on the experience of developing and 'doing' relationships with the participants not only facilitates authenticity and

trustworthiness assessments, but also underscores the necessity of reflexivity as I *lived* the tensions familiar to care staff and families. I *experienced* the need to suspend assumptions and to adopt approaches grounded in deep knowledge of the particular. These reflections may again be helpful to policy makers advancing ‘more person-centred’ approaches; developing deep knowledge takes time. They may also be instructive to people with dementia, family members practitioners and researchers.

The current insistence on using standardised reductive assessment tools throughout the life course, from the over-testing of young school children to the systematic and proactive unsolicited evaluation of cognitive competence in later life, does not sit well with the need to develop deep knowledge. Coupled with the overreliance on measurable outcomes to determine the quality of our lives, this suggests there may be more ‘testing times’ ahead. However, I am mindful of arguments advanced by Davis (2004) and Tremain (2005). These authors suggest that diagnostic expansion and the bias for reductive tests must satisfy some productive element of power, in the case of dementia producing a more palatably reassuring image of ageing and faith in the white coat of medicine. The moral-medical tug-of-war has not been won once and for all. It still possible to lend some weight to the moral end of the rope and pull together to try to restore a better, kinder balance. For this to happen, we need more individual counter-narratives and more critically interrogative accounts, such as those advanced in this study. There also needs to be greater honesty about what is and is not known about dementia and late onset AD in particular. Films such as Carper’s (2016) *Monster in the Mind* may yet increase societal awareness of ‘*the convenient un-truth about Alzheimer’s*’.

Limitations of the study

When thinking about the translation of the research outputs into practice, like all studies, the results of this Narrative Inquiry should be considered in the context of its limitations, as detailed below:

What researchers can know is always limited and I can only ever contribute to understanding in a partial, provisional and perspectival way. My understandings are influenced by the different types of activities undertaken with the participants, shaping the nature of my participation and opportunities for engaging with meaning-making processes. They are also influenced by the nature of relationships developed with the participants, each of which was qualitatively different.

I have used a continuous process of reflexivity to account for my presence in the research, together with a theoretically informed analysis in an attempt to produce responsible knowledge. Although seeking to be reflexive from the outset of the study, there are limits to reflexivity in terms of the degree to which researchers can really know their own subjectivity, and what influences their research. I am therefore cautious about how much I claim to know about what has influenced the research, including my motivations, reading of the literature, the effects of my presence in the field and upon the selections made and interpretations offered in configuring the narratives.

This research was carried out with a small number of people in one small Scottish town and cannot claim to be generalisable. Indeed, generalisability and representativeness are not the aim of Narrative Inquiry. Nevertheless, many of the details found in and across the narratives are consistent with those found in the wider dementia and ageing literature, enhancing the trustworthiness of the findings. These include the mix of individual coping mechanism and 'strategies' used to live well with 'dementia', the varying responses to diagnosis and the privileging of emotional goals.

The study was time-limited, in part to limit the demands on participants, but also to satisfy the constraints of a doctoral research study. Given the push towards earlier diagnosis, and the importance of restoring age relations, longitudinal and intergenerational research that engages directly with the human condition will be critical going forward.

Conclusion

This thesis makes an original contribution to knowledge by combining theory and empirical work to enhance understandings of the social citizenship and narrative citizenship of older people living with dementia. Specifically, it expands current theoretical notions of social citizenship in dementia studies by stepping into the realm of the ordinary and engaging with the human need for recognition as a vital aspect of citizenship-as-practice.

The study also builds on important arguments for a narrative citizenship in dementia studies. The narrative-in-action methodology articulates more fully the relationship between narrative and the everyday practices of citizenship, between narrative and life and the mediating role of narrative in identity configuration. It holds the potential to

elevate the status of narrative as a valued form of evidence with ontological, epistemological and ethical significance. Drawing upon narrative theory, it highlights the importance of narrative in later life and responds to the specific challenges that narrativity can present through the different stages of dementia. When combined with flexible ethnographic data creation methods, the application of narrative theory increases participatory possibilities by utilising the different levels of meaning-making within triple *mimesis*, accessing meaning-making-in-action and evoked memories. The application of narrative theory also enhances the transparency of analyses.

In this study the methodology generates more nuanced understandings of different ways of responding to and living with dementia, illuminating into the diverse contributions made by older people living with dementia through relational, generative and creative practices conducted in the mundane spaces of daily sociability and the private realm. In so doing, it embraces diversity and opens up possibilities for complex self-representations, suspending assumptions of difference. It also engages with temporality, seeing actions, events and people in time, perceived through a dialectic thickening of a past and an implied future. This brings an important third dimension to people's lives, forging connections with possibility and the notion of self-constancy, whereby people intend themselves into the future and resist ascribed deficient identities in explicit and subtle ways.

Many of the more relational and generative contributions made are at odds with individualistic assumptions at the heart of neo-liberal blueprints for citizenship and dominant conceptualisations of achievement and success, and thus may be overlooked. They may also be impeded by the pace of contemporary life and the busyness of the lives of others. The narratives represent ongoing struggles for recognition and also challenge the dominant cultural narrative of loss in implicit and purposeful ways, adding to the 'nascent field of academic narratives of resistance' (Beard, 2016:232). The narratives and accompanying reflections offer insights of potential value to policymakers and diverse practice audiences. Importantly, they present arguments that say something essentially human about ordinary, everyday life with dementia. Diagnostic expansion and catastrophic cultural representations of dementia have resulted in a new culture war and much is at stake for older people and for society. In these testing times, the narratives are a direct response to calls to bring humanity back into considerations of ageing and dementia.

Endless Orchards

"It will be at our peril if we put our faith in the measurable, and dishonour that which lies beyond statement. For it is the immeasurable quality of the spirit that is the true essence of life".

Florida Scott-Maxwell, *The Measure of My Days* (1968:64)

As I struggle to conclude this thesis, I experience my own 'testing times'. I feel that time is evaporating and I am ever conscious of the ticking hands of the clock. Yet there are moments when I simply have to stop the clock and turn my attention inward. I have to reflect upon and 'refigure' the meaning of my doing, the meaning of my ageing and the meaning of time. During these moments, I look back on some key experiences on the Narrative Inquiry landscape. I think of the catalogue of medical appointments and procedures that marked Jim's final weeks at home, and his lament '*in hindsight*'. I puzzle over Mary's wish that his condition was '*normal dementia*'. I think of Hector's mantra '*this is no rehearsal*' and imagine him as a young man reading the slogan painted on a wall, lit up by glorious sunshine, blissfully unaware that it will become his touchstone in the later years of his life. I open the illustrated copy of *This Life that I Have* gifted to me by John and Ann and think of them still delighting in the physical presence of each other.

At other times, I think of Tommy revelling in having a pseudonym and laughing at my '*wee James Bond gadget*', joking '*we're like a couple of spies*'. I think of Grace telling me about the day in the garden when Tommy asked her to sit with him '*while the sun shines*', reflecting '*he'd never have said that before*'. I then think of the poetic beauty of his likening the plaques and tangles of Alzheimer's disease to '*a touch of frost*'. And I return to Chrissie's assertion that people who die suddenly without getting the chance to say goodbye to their loved ones experience a crueller fate than those diagnosed with Alzheimer's disease. I am mindful that she never had the chance to repair the cracks in her relationship with her son. The flower-embossed motto on her living room table advises: '*Don't wait for the perfect moment, take the moment and make it perfect*'.

In 'refiguring' my own life, I recognise the need to invest more in my relationships, to slow down and to ensure that the attempts of older family members to participate and contribute are not impeded by the busyness of my life and a flawed conception of

‘success’. Only then will I too be able, in later life, to enjoy midnight games of hide-and-seek by torchlight – a reward for the heavy spade work conducted over a life time.

Going forward, it seems we need better metaphors. I called the narratives in this thesis ‘fallen fruits’, disconnected from their life source and selected from the wind crop of actions, interactions and stories generously made available to me while walking on the Narrative Inquiry landscape. I later discover that ‘Fallen Fruits’ is also the name of an urban arts project, initiated in San Francisco in response to a call in the fabulously named *Journal of Aesthetics and Protest* for projects that address social and political issues by proposing a solution, rather than raising a critique. The ‘Fallen Fruits’ project mapped out fruit trees along previously neglected walkways through the city, enabling passers-by to share in their abundant resources. The project has since grown exponentially. As an alternative metaphor to the dementia ‘epidemic’ or ‘tsunami’, I borrow from this initiative and offer ‘Endless Orchards’. These ‘orchards’ are home to an abundance of narratives-in-the-making. It would be a shame for this potential to go to waste. What’s needed is a narrative citizenship. I hope this thesis contributes to its realisation.

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Appendix I: Reviewing the Literature



This thesis draws on a broad literature base and I included any material which might provide insights relevant to the overall study aim of exploring everyday life with dementia through a broader societal lens. The literature reviewed included original research, review articles, discussion articles and academic text books. The review combined broad scans of different bodies of literature addressing theoretical, methodological and empirical questions and deep dives through very specific literature searches to gain depth of understanding. The materials were primarily identified through targeted searches of the academic databases, although supervisors and colleagues additionally suggested core texts and useful articles. I found the University's Searcher tool helpful, which scans multiple databases, occasionally conducting searches using specific databases such as Web of Science, PsycInfo and MedLine. The international literature was explored, but limited to English Language. Chapters One through Five each draw upon different bodies of literature and the specifics of my

approach to search and review differed in each case, depending upon the questions I asked of the literature.

Initially I was interested in the different ways in which dementia has been conceptualised, asking the questions: What is dementia? What different understandings are at play? Searches were undertaken using combinations of the search terms: dementia, Alzheimer's disease, cognitive impairment or cognitive dysfunction and theories, models, philosophy, understandings or conceptualisations (singular and plural). I drew upon seminal philosophical texts, particularly the work of Julian Hughes, including edited volumes which brought together a range of perspectives (Hughes et al, 2006) plus books that think about dementia, the relationship with ageing and the issues it raises in contemporary Western society (Hughes, 2012; Hughes, 2013).

As I discuss in Chapter One, I was always interested in approaching the study in a way that would contextualise people's experiences more broadly and the citizenship lens held immediate appeal. However, I was also intrigued by the dominance and continued expansion of the biomedical model and the relationship between dementia and ageing and sought to understand this better. I began by searching for articles considering the problematisation and biomedicalisation of ageing, ensuring to include American spellings in search terms. I then turned to the literature documenting the history of dementia and the benefits and issues surrounding the increasing biomedicalisation cognitive impairment in later life. A few discussion articles considering historical developments were widely cited, notably Fox (1989), Holstein (1997) and Whitehouse and George (1989).

Insights distilled from the established body of literature were augmented by in-depth accounts of recent developments in the field – the fresh chapters that had subsequently been added. In this respect, I accessed a number of books, including those bringing diverse perspectives to the discussion (e.g. Cohen and Ballinger, 2006) and those addressing a particular question or issue (e.g. Lock, 2013). These texts were extensively researched and served as a useful reference source, and I retrieved numerous articles that I thought would deepen my understanding. I also sought to ensure that I kept sight of any new developments by repeating searches periodically, restricting the search parameters to volumes published after my initial search (e.g. Beard, 2016). This body of literature is presented in Chapter Two.



Literature searches were also conducted to learn more about the different 'social models' identified e.g. using search terms dementia (or alternatives) and disability or 'social model of disability' or citizenship. Again, I was interested in understanding how these models were conceptualised before considering their empirical application. Indeed, a key issue to emerge within these discussion articles was the limitations of the existing empirical research evidence, notably the lack of attention to heterogeneity of people with dementia and to the wider societal context. I therefore sought to develop my own broad understanding of key themes within the established body of literature, initially drawing upon systematic reviews of studies investigating the subjective experience of dementia, identifying referenced articles of particular interest, and then conducting searches repeating the search terms employed by the systematic review and restricting the search to articles published since the reviews were conducted. I also conducted more targeted searches to develop my understanding of specific issues such 'insight' and 'awareness', 'acceptance and denial' and topics such as 'activity', 'occupation' and 'everyday life'.

I located my research interest in what has been called the 'fourth moment' in understanding in dementia studies. This resulted in a review of all articles meeting the search criteria 'dementia' (or alternatives) plus citizenship. From there the literature search might be likened to a chain reaction or snowballing, as additional material was identified by using the reference and citation lists of the journal papers identified through the database searches. I accessed books and journal articles by highly cited contributors to developments within dementia studies, notably Bartlett and O'Connor (2010). Other articles drew upon an ethic of care perspective and I also accessed the works of extensively cited authors, particularly Tronto (1993), Sevenhuijsen (1998; 2003) and Barnes (2011; 2012). I accessed the wider literature on citizenship and related concepts, notably recognition, accessing books by noted authors. The scope of the literature examined developed as the study progressed and as important issues, gaps in knowledge and the focus of the research became more defined. This included searches using the terms combinations of the terms 'couplehood', 'identity development', 'narrative' and 'temporality' plus 'old age', 'ag(e)ing and dementia.

Additionally, I searched the literature to identify methodological approaches of potential interest, both using and purposefully omitting 'dementia' as a search term. I

sought to develop a broad understanding of possible theoretical and methodological combinations and then assess their likely utility in research with older people with dementia. It was through a search using the terms 'everyday activity', 'ordinary', 'biomedical' and 'narrative' that I came upon the narrative-in-action methodology. This drew upon Paul Ricoeur's (1994) early narrative theorising and I initially purchased a copy of *Time and Narrative Volume I*, later engaging more deeply with Ricoeur's work, accessing several books and journal articles. I also accessed literature on my chosen methodological approach, Narrative Inquiry, including core texts by Clandinnin and Connelly (2000) and Polkinghorne (1995).

Appendix II: Ethical Approval from the University School

DOCUMENTATION CHECKLIST			
j) ^{DC1} Does your research project require extraction or collection of data abroad? (✓)			
<input checked="" type="checkbox"/> No <input type="checkbox"/> Yes	No Yes	If 'No' Skip to Q2. Local Ethical review needed, please confirm (✓) electronic attachment of: Application to ethical review panel in country of data collection (in English) + copy of letter of approval	
k) ^{DC2} For the purposes of this research study, will you access identifiable ² information on any NHS patient? (✓)			
<input checked="" type="checkbox"/> No <input type="checkbox"/> Yes	No Yes	If 'No' Skip to Q3. Please confirm (✓) electronic attachment of: Caldicott Guardian approval for use of NHS data (or confirmation that it is not required)	
l) ^{DC3} Does the project require ethical review by an external UK committee e.g. NHS REC or Social Work?			
<input type="checkbox"/> No <input checked="" type="checkbox"/> Yes	No Yes	If 'No' Skip to Q4. Please confirm (✓) electronic attachment of: NHS REC (IRAS) / other application form + copy of letter of approval NOTE: You are <u>not</u> required to complete University ethical review forms. Skip to Q6	
m) ^{DC4} Unless you answered 'yes' to 3, you must also obtain ethical approval through the University of Edinburgh process. Please submit a Level 1 form (with 'Methods' summary) and, if indicated, a level 2-3 form as well.			
SHSS Ethics paperwork		Forms: level	Summary of 'Methods'
Please indicate the SHSS Ethics forms completed herewith (✓):		1 2/3	
n) ^{DC5} If you have completed the Level 2/3 form please list any additional documentation provided in support of your application (E.g. Disclosure, consent form, participant information, GP letters etc.)			
Documentation Name	These should reflect content	(✓)	Documentation Name
(✓)	(✓)	(✓)	(✓)
o) Signatures			
Karen Barrie		30/6/15	Date signed
Applicant's Name	Applicant's Signature		
Prof. Charlotte Clarke		30/6/15	Date signed
Supervisor's Name	Supervisor's Signature		
Ethical approval agreed 29th July 2015 Marion Smith SS4 Lead Ethics Review			
¹ 'Identifiable information' refers to information that would allow you to know, or be able to deduce, the identity of a patient. The most common examples of this would be accessing medical records or similar, or accessing a database that includes patients' names. ² Not required for staff applications.			

Appendix III - Favourable Opinion from NHS REC SS02

Lothian NHS Board

South East Scotland Research
Ethics Committee 02



Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000

www.nhslothian.scot.nhs.uk

Date: 03 June 2015
Your Ref:
Our Ref:

Enquiries to: Joyce Clearie
Extension: 35674
Direct Line: 0131 495 5674
Email: Joyce.Clearie@nhslothian.scot.nhs.uk

03 June 2015

Mrs Karen Barrie
ISSH, Doorway 6
Old Medical School, Teviot Place
Edinburgh
EH8 9AG

Dear Mrs Barrie

Study title: Understanding the 'agency-structure' dynamic in the everyday activities of older people with dementia living at home in an urban setting
REC reference: 15/SS/0076
Your Ref: n/a
IRAS project ID: 165441

Thank you for your letter of 1 June 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair. We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Ms Joyce Clearie, joyce.clearie@nhslothian.scot.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.



INVESTORS
IN PEOPLE



Healthy
Working
Lives

Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair: Mr Brian Houston
Chief Executive: Tim Davison
Lothian NHS Board is the common name of Lothian Health Board

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper (Cover Letter)	1.0	14 April 2015
GP/consultant information sheets or letters (Participant Identification Centre Information Sheet)	1.0	02 April 2015
GP/consultant information sheets or letters (UEA: Notification of Patient Recruitment to Study)	2.0	22 May 2015

Yours sincerely



Lindsay Murray
Chair

Email: joyce.clearie@nhslothian.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: Jo-Anne Robertson
Mr Gavin Robertson, NHS Lothian

Appendix IV: Letter of Approval from NHS Lothian

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

FWLM/approval

24 June 2015

Mrs Karen Barrie
ISSH, Doorway 6
Old Medical School
Teviot Place
Edinburgh
EH8 9AG



Research & Development
Room E1.12
Tel: 0131 242 3330

Email:
R&DOffice@nhslothian.scot.nhs.uk

Director: Professor David E Newby

Dear Mrs Barrie

Lothian R&D Project No: 2015/0265

Title of Research: Understanding the 'agency-structure' dynamic in the everyday activities of older people with dementia living at home in an urban setting

REC No: 15/SS/0076

Participant Information Sheet:

Version 2 dated 22 May 2015

Protocol: Version 1 dated 2 April 2015

Consent Form:

Version 2 dated 22 May 2015

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

We note that NHS Lothian is participating in this trial as a Participant Identification Centre (PIC).

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

A handwritten signature in black ink that reads 'Fiona McArdle'.

Ms Fiona McArdle
Deputy R&D Director

Appendix V: Letter Approving Substantial Ethical Amendment

Lothian NHS Board

South East Scotland Research
Ethics Committee 02

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EQ
Telephone 0131 538 9000



www.nhslothian.scot.nhs.uk

Date 24 March 2016
Your Ref
Our Ref

Enquiries to: Joyce Cleerie
Extension: 35674
Direct Line: 0131 485 5674
Email: Joyce.Cleerie@nhslothian.scot.nhs.uk

24 March 2016

Mrs Karen Barrie
ISSH, Doorway 6
Old Medical School, Teviot Place
Edinburgh
EH8 9AG

Dear Mrs Barrie

Study title:	Understanding the 'agency-structure' dynamic in the everyday activities of older people with dementia living at home in an urban setting
REC reference:	15/SS/0076
Protocol number:	n/a
Amendment number:	AMO1 SA1-1 modified amendment
Amendment date:	11 March 2016
IRAS project ID:	165441

Thank you for submitting the above amendment, which was received on 17 March 2016. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 10 March refers).

The modified amendment was reviewed by the Sub-Committee in correspondence. A list of the members who took part in the review is attached.

Ethical opinion

No significant ethical issues were raised with this modified amendment.

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:



Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EQ

Chair: Mr Brian Houston
Chief Executive: Tim Dawson
Lothian NHS Board is the common name of Lothian Health Board

Appendix VI: Participant Identification Centre Information Sheet

Understanding Everyday Agency (UEA_GP_PHC Letter Version 1 02/04/2015)



Interdisciplinary Social Sciences in Health
School of Health in Social Science
Medical School, Teviot Place
Edinburgh
EH8 9AG

Telephone: 0131 651 6671
Fax: 0131 650 3891

10/06/2015

Information Sheet for GP Practices Considering Acting as Participant Identification Centres

Dear *(Lead GP Name)*

Understanding Everyday Agency Research Study: How do people living with memory problems or dementia go about their everyday activities: What helps and what makes things more difficult?

Many thanks indeed for your initial expression of interest in supporting the above study. The research study recently met with a favourable ethical opinion from the South of Scotland Research Ethics Committee. I am now writing to provide more detailed information about the study and to outline what acting as a Participant Identification Centre would entail.

What is the Study Purpose?

This qualitative study seeks to contribute to the body of research committed to finding better ways of supporting people with dementia to live positive lives. It sets out to engage with older people with dementia as participants and stakeholders in ordinary social life. The study contends that if older people with dementia are not simply to remain at home for as long as possible, but are to live well at home, it is vital that we understand how they go about doing the things that matter to them, at home and in their local communities, what helps and what makes life more difficult. By exploring the everyday activities of a small but diverse group of older people with dementia and locating them within a broader context, the study aims to build upon current theoretical understandings of dementia. It also aims to identify the implications for mainstream health, social care and wider public policy, and ultimately for society.

Who is Conducting the Research?

My name is Karen Barrie. I have worked in health and social care service improvement and applied policy contexts for many years and have developed a particular interest in improving the experiences of older people living with dementia using participatory and inclusive methods. (A career resume is available on request). Last year I was delighted to obtain a Principal's Career Development PhD Scholarship from the University of Edinburgh to allow me to conduct this research study. The University of Edinburgh and NHS Lothian are co-sponsoring the study, and it is being supervised by Professor Charlotte Clarke, Head of the School of Health in Social Science, University of Edinburgh.

Who is the Study Seeking to Recruit?

This study sets out not only to involve people in meaningful ways, but also to ensure that diverse perspectives are included. Ultimately the study seeks to recruit around **12** people with very different social locations and life circumstances. It will be important not to overlook the perspectives of individuals who might be classed as multiply deprived or disadvantaged. The study plans to identify potential participants through three or possibly four GP practices in NHS Lothian serving patient populations with a mix of deprivation categories. The eligibility criteria are as follows:

- men and women
- aged 65 or over (no upper age limit)
- with a diagnosis of dementia
- living at home (either alone or with others)
- able to give consent (written, verbally or non-verbally)
- and registered with one of the GP practices supporting the study

What Will Be Expected of Participating Patients?

It is anticipated that each participant will meet with me on a maximum of seven occasions over a period of not more than six months, and at times and in settings of each participant's choosing. Specifically, an initial introductory meeting will be followed by five data generation sessions and a final wrap up meeting.

On three of these occasions we will spend time doing the things that the person would usually do and would feel comfortable doing with me. I will follow the natural stream of their 'ordinary' everyday routines and engage in whatever activities are initiated, such as hobbies, gardening, meal preparation, tidying up, shopping or socialising informally. These sessions will be interspersed with two participant observation sessions that will take place in a social setting or at an event that holds slightly more

personal, social or cultural significance for the participant, such as attending a family gathering, church, occasional outing or even a trip to the hairdresser.

While there will be no direct benefits for participants, most people find taking part in research of this type a very positive opportunity. Very occasionally it can be upsetting and support arrangements will be in place should this happen, notably through the local Alzheimer's society.

What Would Being a Participant Identification Centre Entail?

As Participant Identification Centres, GP practices are asked to identify potential patients who fit the study inclusion criteria and to send them a pack containing a Participant Information Leaflet and a letter inviting them to contact me if they would like to take part or to know more. (Copies of the Letter of Invitation and Participant Information Leaflet are enclosed). Both have been approved by South of Scotland Research Ethics Committee and must not be altered. As the study is being undertaken for the purposes of doctoral research, there is no dedicated research budget to cover administrative costs. I will however provide envelopes, postage stamps and hard copies of the Participant Information Leaflet. It is recognised best practice for the Letter of invitation to come from the GP on practice headed paper, and an electronic copy of the letter will be supplied to support this. However, this aspect of the process can be negotiated locally to minimise the workload for the practice.

The workload involved in supporting the identification of three or four participants per practice is not expected to be onerous, but as identification cannot be fully automated through a database search, it will require the input of time from practice staff. Specifically, there may be reasons why it is not appropriate to invite patients meeting the inclusion criteria to take part in the study. Potential participant identification will therefore require members of the clinical care team to use their knowledge of the person, professional judgement and discretion in applying the set exclusion criteria and possibly criteria in addition to those identified below. The study will exclude people:

- diagnosed with dementia within the previous 3 months (to allow time for adjustment)
- with a terminal illness and who are expected to live for less than one year
- who have experienced recent significant life changes such as a bereavement
- who are experiencing family issues or illness
- who may be in the process of moving to a care home
- who are or have recently been involved in another study

What Will Happen after the Information is Posted Out?

Potential participants who are interested in taking part will be asked to contact me directly. They will have the opportunity to talk to me and ask any questions by phone and an initial meeting will be arranged, which will allow us to get to know each other and enable them to find out more before they make a decision.

Subject to the person's agreement, the practice will be notified by letter whenever a potential participant consents to take part in the study, allowing the patient's record to be updated. The concept of 'process consent' will be used, whereby consent will be revisited at and throughout each visit to make sure taking part is still something that the person wants to do. In the event that there is doubt about a person's continued ability to give consent to take part during the course of the study, I will make contact with his or her GP.

Further Information about the Study

I hope that this information sheet will have provided enough information for you to decide if supporting the identification of potential participants is something that your practice might agree to. You may of course have further questions. A full research protocol is available if of interest to you. If you would like to discuss the study or meet with me to find out more, please contact me on 07756778271 or email s1356228@sms.ed.ac.uk

Many thanks indeed for your time and consideration.

Yours sincerely



Karen Barrie

Principal's Career Development PhD Scholarship Student
Interdisciplinary Social Science in Health
School of Health in Social Science, University of Edinburgh
Email: s1356228@sms.ed.ac.uk
Telephone: 07756778271

Appendix VII: Participant Invitation Letter from GP

Understanding Everyday Agency (UEA) Invitation Letter Version 1 02/04/2015

GP PRACTICE LETTER HEAD

<Patient Name

Our Ref. <Study / Admin Code>

Address Line 1

Address Line 2

Address Line 3

Postcode>

Date: DD/MM/YYYY

Dear <Patient Name>

<Practice name> is supporting a research study being carried out by the University of Edinburgh. We have been asked to pass on details of this study to people aged 65 and over registered with the practice. We are contacting you to ask if you would be interested in taking part.

This research is concerned with understanding how people who have memory problems or dementia go about their everyday activities at home or in their local communities. The study aims to find out what helps people to do this, and the things that can make life more difficult. The enclosed information leaflet explains the study in more detail.

Taking part in this study is voluntary. If you decide not to take part it will not affect the standard of care you receive from your GP in any way.

If you are interested in taking part, or would like to find out more about the study before deciding, please contact the researcher, Karen Barrie, at the University of Edinburgh on [MOBILE]. If she is not available, please leave her a message and she will contact you as soon as possible.

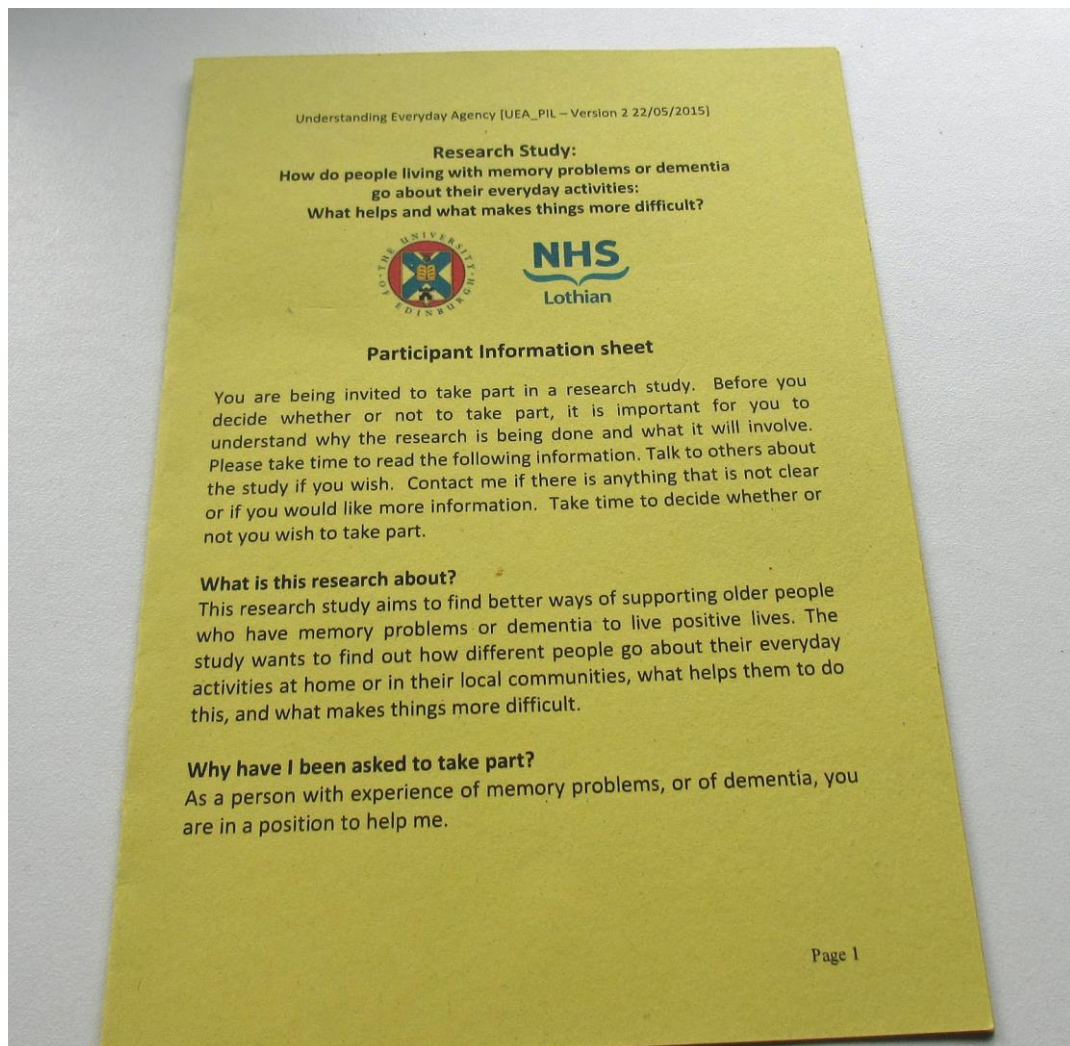
Thank you for considering this invitation.



Yours sincerely

<Lead GP signature and name>

Appendix VIII: Participant Information Leaflet

“The Little Yellow Leaflet”



<p>What happens next? If you decide to be part of this work, I will meet with you at your home or at a place where you feel most comfortable. We will talk through the research study and agree the next steps. You may prefer to have a family member or friend with you when we meet.</p> <p>With your consent I will inform your GP that you are taking part.</p> <p>Who should I contact for further information? I hope that this information sheet will have provided enough information for you to decide if this is something that you might consider doing. You may have further questions. If so, please don't hesitate to get in touch with me, Karen Barrie, on 07756778271 and I will call you back to save you the cost of the call. Or you can email me at s1356228@sms.ed.ac.uk</p> <p>If you would like to discuss this study with someone independent of the research team, please contact Professor Heather Wilkinson on: 0131 651 1832 or email: h.wilkinson@ed.ac.uk</p> <p>Other Contact Information If at any time you would like to discuss your situation, then local support is available by contacting: Alzheimer Scotland Freephone Helpline on 0808 808 3000</p> <p>Should you wish to make a complaint about the study please contact: NHS Lothian Complaints Team 2nd Floor, Waverley Gate 2 - 4 Waterloo Place Edinburgh EH1 3EG Tel: 0131 465 5708 Email: complaints.team@nhslothian.scot.nhs.uk</p> <p>Many thanks indeed for reading this information sheet.</p>	<p>Understanding Everyday Agency [UEA_PIL – Version 2 22/05/2015]</p> <p>Research Study: How do people living with memory problems or dementia go about their everyday activities? What helps and what makes things more difficult?</p> <div style="text-align: center;">   </div> <p>Participant Information sheet</p> <p>You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information. Talk to others about the study if you wish. Contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.</p> <p>What is this research about? This research study aims to find better ways of supporting older people who have memory problems, or dementia, to live positive lives. The study wants to find out how different people go about their everyday activities at home or in their local communities, what helps them to do this, and what makes things more difficult.</p> <p>Why have I been asked to take part? As a person with experience of memory problems, or of dementia, you are in a position to help me.</p>
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Page 4

Page 1

<p>Do I have to take part? No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. I will also check to see if you still feel okay with it as we go along. Deciding not to take part or withdrawing from the study will not affect the care or any services that you receive.</p> <p>What am I being asked to do? Taking part will mean meeting with me several times over a few months. You will choose the times that we meet to fit in with your plans, but usually the study will not last more than six months.</p> <ul style="list-style-type: none"> An initial meeting will allow us to get to know each other better, to talk through the study and agree the next steps. On three of our meetings we will spend time doing the things that you would usually do and would feel comfortable doing with me, such as shopping, meal preparation, tidying up, relaxing, gardening or hobbies. Each of these meetings will last between half an hour and two hours. You will decide how long each meeting should last and where it will take place. I will use a machine to record our talks and I may also write notes. On a different day, I hope to accompany you to an event or to a place that is a bit more special to you such as attending a family gathering, club, church or trip to the hairdressers. You will again decide how long this visit will last, but I would not expect to take up more than three hours of your time. During the final wrap-up and thank you meeting we will review the information gathered to make sure you are happy with it. <p>During our meetings we may also take photographs of things that strike you as important. If you agree, we will later talk about the photographs. No one else will see the photographs, unless you want to show them to family members or friends.</p>	<p>What are the benefits and risks of taking part? Most people find taking part in research a very positive opportunity. Very occasionally it can be upsetting and if this happens there will be people who can support you.</p> <p>What will happen to the information that is gathered?</p> <ul style="list-style-type: none"> All information gathered will be treated in confidence, anonymised and stored in a secure place. Only I will handle the information. All anonymised information gathered will be used even if, for whatever reason, you withdraw from the study. The information will continue to be stored securely after the study has finished and will be destroyed after five years. <ul style="list-style-type: none"> When the study is finished the findings will be written up as a thesis, conference presentations and papers. A research study website will also be created and will be available to the public. You will be offered a hard copy of a research summary report that I will post to you, if this is of interest to you. Your name will not appear in any report or anything to do with the research work. <p>Who is carrying out the research? My name is Karen Barrie. I have worked to try to improve health and care services for older people for many years. I have experience of involving people who have memory problems or dementia in my work in lots of different ways. Last year I was delighted to win a career development PhD scholarship at the University of Edinburgh to allow me to carry out this research. The University of Edinburgh and NHS Lothian are sponsoring this study.</p> <p>Who has reviewed the study? The study proposal has been reviewed by an independent group of people, called a Research Ethics Committee (REC). A favourable ethical opinion has been obtained from the South of Scotland REC.</p>
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Page 2

Page 3

Appendix IX: Participant Consent Form

Understanding Everyday Agency [UEA_PC - Version 2 22/05/2015]

How do people living with memory problems or dementia go about their everyday activities-
What helps and what makes things more difficult? **Consent to participate**



Please place your initials in the appropriate box for each item below:	Initials
I have read and fully understand the yellow information leaflet for participants [UEA_PIL_Version2 22/05/2015] and have had the opportunity to ask any questions I may have about the research	
I understand that information collected will be managed by Karen only and will be destroyed after a period of five years	
I agree to my conversations with Karen being recorded and understand that the recordings will be typed out word for word and then destroyed	
I agree to Karen taking photographs and understand that she will not show these photographs to anyone else	
I agree to my GP being informed of my decision to take part in this study	
I agree that anonymised information can still be used even if, for whatever reason, I withdraw from the study	
I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the sponsors (NHS Lothian and the University of Edinburgh) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my data	
I consent to take part in the research study about the everyday experience of living with memory loss or dementia	

Signature of participant

Name Date.....

Signature of person taking consent

Name Date.....

To be completed only where the participant is unable to give consent in writing:

Signature of person witnessing consent:

Name Date.....

[2 Copies completed: 1 copy to be retained on research study site; 1 Copy to be retained by the participant]

Karen Barrie, Principal's Career Development PhD Scholarship Student, School of Health in Social Science

Doorway 6, Old Medical School, Teviot Place, Edinburgh EH8 9AG

Email: s1356228@sms.ed.ac.uk

Telephone: 07756778271

Appendix X: Study Amendment Letter – “Couplehood”

UEA_AS_PS_Version1 11/03/2016



School of Health in Social Science
Medical School, Teviot Place
Edinburgh
EH8 9AG

Telephone: 0131 651 6671
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Date:

Dear Mr and Mrs <SURNAME>

Research Study: How do people living with memory problems or dementia go about their everyday activities: What helps and what makes things more difficult?

LETTER OF AMENDMENT TO THE STUDY

Many thanks for your ongoing contributions to the above study.

When the study began I had not anticipated that some people consenting to take part would identify themselves very much as part of a couple, and carry out their everyday activities together. As I have had the opportunity to spend time with you both, I have come to realise that I should have included the option for <spouse name> to take part in the study on a more formal footing. This would have been more in keeping with your expectations as to how your joint contributions will be described in the study write up, and more consistent with the way you go about your daily lives.

I recently submitted a proposed amendment to the study and the relevant bodies have given a favourable opinion. I am now able to offer <spouse name> the option of consenting to take part in the study too.

I should stress that this is simply an option. It is entirely up to <spouse name> whether or not to consent to take part. I have set out what this would mean below. It is important that you take your time and think about this.

What would this mean?

As we previously agreed, during our meetings I use a machine to record our conversations and I also write notes about the activities that we carry out together. If <spouse name> does consent to participate in the study, when I come to write up the study this would allow me to include the things that <spouse name> says during these activities and to describe the things that you both do. I would use the false names that we agreed during our first meeting.

When we have our final wrap-up and thank you meeting, we would review the information gathered to make sure that you are both happy with it.

All information gathered would continue to be treated as described in the yellow Participant Information Leaflet that you received about the study. This stated that:

- All information gathered will be treated in confidence, anonymised and stored in a secure place. Only I will handle the information.
- All anonymised information gathered will be used even if, for whatever reason, you withdraw from the study.
- The information will continue to be stored securely after the study has finished and will be destroyed after five years.
- When the study is finished the findings will be written up as a thesis, conference presentations and papers. A research study website will also be created and will be available to the public.
- You will be offered a hard copy of a research summary report that I will post to you, if this is of interest to you.
- Your names will not appear in any report or anything to do with the research work.

I will leave this letter with you to give you time to think about it, and to come up with any questions that you might have. When we next meet, I will revisit the letter with you again. If <spouse name> agrees to participate more formally, I will ask <him / her> to sign a consent form called 'Consent to Participate: Spouse of an Existing Research Participant [UEA_FM_PC_Version 2 11/03/2016]'. You will be given a copy of this consent form to keep.

If you have questions before we next meet, please don't hesitate to give me a call. Or if you would like discuss this with someone independent of the research team, please contact Dr. Marissa De Andrade on 0131 651 5554 or email marisa.deandrade@ed.ac.uk

Many thanks indeed once again for your participation in the study and for making me think about 'couplehood' in a very different way.

Yours sincerely



Karen Barrie
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Should you wish to make a complaint about the study please contact NHS Lothian Complaints Team
2nd Floor, Waverley Gate, 2 - 4 Waterloo Place
Edinburgh EH1 3EG
Tel: 0131 465 5708
Email: complaints.team@nhslothian.scot.nhs.uk

Appendix XI: Spouse Consent Form

Understanding Everyday Agency (UEA_FM_PC - Version 1 11/03/2016)

How do people living with memory problems or dementia go about their everyday activities-
What helps and what makes things more difficult?

Consent to Participate: Spouse of an Existing Research Participant



Please place your initials in the appropriate box for each item below:	Initials
I have read and fully understand the <i>Amendment to the Study Letter</i> [UEA_AS_PS_Version1 11/03/2016] and have had the opportunity to ask any questions I may have about the research	
I understand that information collected will be managed by Karen only and will be destroyed after a period of five years	
I agree to my conversations with Karen being recorded and understand that the recordings will be typed out word for word and then destroyed	
I agree that anonymised information can still be used even if, for whatever reason, I withdraw from the study	
I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the sponsors (NHS Lothian and the University of Edinburgh) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my data	
I consent to take part in the research study about the everyday experience of living with memory loss or dementia	

Signature of participant

Name Date.....

Signature of person taking consent

Name Date.....

.....

[2 Copies completed: 1 copy to be retained on research study site; 1 Copy to be retained by the participant]

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Appendix XII: Sample Field Notes

M02 – Self-Selected Pseudonym Tommy

A Visit to the Chapel

Waiting for the bus

It is just before quarter to 11. It is a cold, windy day and there is a light drizzle in the air. I am parked across the road from the bus stop where I have arranged to meet Tommy. I arrived very, very early, having allowed time for possible traffic delays that never materialised. I am reading through the notes of my last meeting with Tommy when Grace phones me from her mobile. She apologises and says that she must have been looking at the Sunday timetable, that the bus won't get in until 11 at the earliest and she didn't want me standing about in the cold. I thank her, tell her where I am, and ask 'so, is that Tommy on the bus now?' Grace tells me that she has caught the bus too, having 'decided at the very last minute to go on to M&S at < local shopping centre > to see if they have an Easter meal deal on'. *(I suspect that she will have had second thoughts about Tommy getting off at the right bus stop, particularly as this will not be familiar to him, and am struck by the way she wraps this up to protect him)*. I ask Grace if I should get the bus back to the house with Tommy afterwards, but she assures me that he will be fine getting the bus on his own because it stops right outside the door.

I get out of the car at 10:55 and stand at the bus stop, watching the 'bus due' clock count down. When the bus turns the corner I can see that Tommy is at the front of the queue of people waiting to get off, smiling and joking with the driver in his own inimitable way. *I find myself smiling and realise that I am genuinely pleased to see him*. I salute when he sees me as he steps off the bus. He comes over and grabs the fur of my jacket collar and says 'are you still not feeding that cat'. I laugh *(noting that he has remembered my coat and his previous joke about it)* and we both wave to Grace as the bus drives off. She waves back heartily and she is smiling, but I note that she looks very tired.

At this point we cross the road. There is no pavement on the other side and we have to walk across a very muddy extended grass verge round the side of a war memorial. Tommy says, 'Jeez, where am I taking us'. I then say 'I'll just follow your lead Tommy' and he says 'more fool you'. As we walk down the road towards the chapel I ask about Grace's flu and if he managed to escape it. He tells me that she's been 'awfy tired', that he had it too, but wasn't too bad with it as he's 'a hardy soul'.

Reflections on the method

The road leading to the chapel is quite long and without pavements. It is deserted. It is very windy and there is a tractor in the field to our left. *(I am holding my audio recorder in my right hand as we walk, but large parts of the conversation are carried off by the wind or drowned out by the tractor. This is a known limitation of the 'walk-and-talk interview'.* Alsaker, who 'pioneers' the enacted narrative method, does not audio record at all during shared activities. *Instead she records everything as soon as possible after the event, 'replaying' the unfolding scenes in her mind frame by frame, capturing the details using a voice recorder – then later typing up. I have found this approach works well for me, but I like*

to 'back up' with audio recorded dialogue where it makes sense to do so. I also find the 'difficult to decipher' audio still serves as a useful sense check, hence my use of the recorder as we walk, even though I know the sound quality will be poor in these blustery conditions).

Back in the bad books again

Initially we talk about the weather and the signs of spring – or lack of them, prompted by the weather and what we see in the fields. As we continue some distance down the road Tommy says 'now mind, I've not been down this way before, so I could be getting us lost'. I point to the visitor centre entrance up ahead and say 'I think you're doing just fine'. He looks directly at me and says 'I wouldnae be too sure about that'. When I ask 'why's that?' he replies 'och, I've been back in the bad books again'.

One for sorrow

I am mindful of Grace telling me there have been 'quite a few more mix-ups' but don't want to push the issue. I wait to see if he expands and he goes on to say 'I'd like to say it's other folks not, not ..., but.....' I prod, repeating 'but?' and Tommy adds 'I've gotten it wrong a few times'. He sounds a bit fed up. (*Tommy has previously told me several times about his inability to learn at school, being the black sheep of the family, and has also frequently repeated the story of his trip to the GP when he got the 'four crosses' on the questionnaire that set things in motion regarding his diagnosis. This 'getting things wrong' is a recurrent theme in the early and latter parts of his life story and I deliberately don't ask for details*). I decide to ask him how he feels about that. After a long pause he says 'Grace is ... she's... I've started calling her my minder. (*I recall that Tommy didn't want people from his Church thinking that I was his minder on our first outing*). Cannae say I'm thrilled about it mind, but dare say I'm lucky or.... He then points out a magpie in a nearby tree, saying 'one for sorrow' [*is this his way of saying how he's feeling – about the shift in the relationship with Grace, about the alternative, or a total coincidence?*]

Before I have the chance to follow up, Tommy immediately starts giving me a lecture about magpies, which I find a bit tricky to follow. It centres on various colourful examples of magpies raiding birds' nests, killing baby birds in savage fashion, chucking them out of their nests, and basically 'hell bent on wiping out all our song birds'. (*I think some examples are recent, some from when he was growing up, and they run into each other ~ I'm not sure if this is a distraction technique, which he's used a few times, or if it is something different, triggered by the magpie sighting and the notion of 'sorrow'. I am aware that I am listening hard (I eventually conclude too hard) for the metaphor. Unlike some of Tommy's earlier stories, this one is self-contained. I note the change in narration style*). Tommy concludes by saying that 'their numbers are up' and 'it's high time we had a cull'. By the time he finishes we have reached the entrance to the visitor centre adjacent to the chapel.

Two for joy

When we go inside Tommy starts his usual patter and chats away about 'this being some set up' to the young man behind the counter, whose badge reveals his name is 'Mike'. Tommy uses his bank card to pay for his ticket, concentrating when entering his pin number, but doing so without any hesitation, and then, on removing his card jokes 'I could buy a small car for that, Mike'. I pay for my ticket, securing a concession by using my

student card, and Mike hands over both tickets saying 'so that's one student and ... two students'. Tommy has a good chuckle at the idea, saying 'I've been called many things, but that's a first. Student'. He looks absolutely delighted. *(Again I am mindful of Tommy's numerous references to his difficulties at school, lack of educational attainment and in particular being 'put in with the useless lot', so I sense the greater significance of this seemingly throw-away remark).*

A surprise 'admission'

Mike asks if we have been before and we both say 'no'. Tommy adds that 'it's a disgrace'. He goes on to say that when he saw a programme about it on the telly the other week, he decided that it was 'high time' he paid a visit. He then adds, 'I've brought my wee sister with me' and winks. Mike smiles at me. *(In our previous outings, when Tommy has been asked who I am by people known to him, he has joked that he's traded his wife in for a younger model, or that I'm just after his money etc. I am interested that Tommy has taken the initiative / felt the need to account for my presence, and also that the relationship that he has chosen by way of explanation has changed to 'wee sister'. I am wondering if there is something in this, or if it has simply been tailored on account of Mike's age and because Mike is unknown to Tommy).*

Mike asks Tommy if he's be interested in getting the annual pass and Tommy answers 'well son, I've got Alzheimer's, so likely I'll no remember what I've seen after today. Dare say I could come back a few times' and has a chuckle. *I am really surprised to hear Tommy admit to having Alzheimer's in this way and wonder if he is becoming more comfortable with the idea, as previously he has been very keen to keep it from people. However, I am keen not to interrupt the flow of his interaction with Mike and so don't ask about it, but make a mental note.*

Spoiler Alert

Tommy has brought the camera that his granddaughter gave him for Christmas with him, but there is a big sign up behind the counter saying 'no photography inside the chapel' and Tommy asks Mike 'what's this sign about'? Mike explains that you can take photos outside, but unfortunately not inside the chapel. Tommy questions Mike's explanation, saying that when he watched the TV programme, 'there were loads of folk inside with big fancy cameras, all snapping away'. *I admire the certainty of Tommy's challenge.* Mike tells him that he's quite right, that you used to be able to take photographs. He goes on to explain that the chapel flooring inside is quite uneven and that one American lady had fallen over while looking up to take a photograph, banging her head badly, and she had sued them. He adds, 'so no more photos' and shrugs. *(I note that Mike explains this to Tommy carefully, but not in a patronising way, and he has not changed his tone or way of interacting since Tommy declared his Alzheimer's).* Tommy responds quite loudly 'typical bloody yanks, spoiling it for everyone' and draws a few strange looks, including from a small group of visitors nearby who I strongly suspect are American! *(I don't feel at all embarrassed, which I know I would if say my mother-in-law made such a remark, but instead I am mildly amused. I find my own reaction interesting).* Tommy thanks Mike for his help, who tells us to enjoy our visit, and we move on.

Put that in your handbag

As we follow the signs to the chapel, Tommy hands me the leaflet and says 'can you put that in your handbag', adding 'I'll forget all about it if I shove it in my pocket'. *(I am acutely aware that I am changing Tommy's visit by being there, but also accept that this is in fact always the case. I am rarely 'just following the flow'. I also reckon that asking a woman to put something in her handbag is an established cultural practice that I rarely stop to question, it is something he would likely ask Grace to do with or without Alzheimer's, and I am maybe overthinking Tommy's request because he also used the 'F word' - 'forget').* I put the leaflet and receipts in my bag and Tommy nips into the gents before we go through the doors leading to the chapel, saying his 'bladder is still playing dictator'. (He has previously told me he attributes this to his Aricept medication).

Master craftsman and the broken head

We make our way outside and are both struck by the coldness of the wind after the warmth of the visitor centre. The drizzle persists, but thankfully but hasn't turned to rain. Tommy wants to take a few photos outside the chapel, and I take one or two of my own. Tommy takes his time framing the photographs and is very comfortable using the camera. We then go inside the chapel and slowly begin to make our way round. There are so many carvings it is all a little overwhelming. Tommy picks up a laminated A3 sheet near the entrance. It is a picture of the interior of the chapel with the main attractions denoted by a numeric key. There is a short description for each. I try to follow Tommy's lead and mostly we chat about the various carvings, trying to orient ourselves using the A3 sheet. Tommy is fascinated by the craftsmanship of the ceiling and talks freely and enthusiastically about his days working as a plasterer and how he got started. I have heard (and written up) these anecdotes before, particularly the details concerning the difficulties he encountered learning to use the equipment as a result of being left handed. I realise the possible import of his re-telling of particular stories *(and later revisit my earlier notes to asterisk those he repeats)*, but focus on the new insights below.

When we discussed the possibility of visiting the chapel during our last meeting, Tommy told me the legend behind the 'Apprentice Pillar', which holds that the master mason returned from his travels overseas to find that his young apprentice, inspired by a dream, had created the beautifully ornate pillar. In a jealous rage, the mason struck the apprentice on the head with his hammer, killing him instantly. The pillar holds a fascination for Tommy and we spend a long time looking at the intricate details of the carvings that snake round it. The information sheet alludes to another carving, allegedly of the apprentice's head, in another part of the chapel, but the head carving is not amongst those numbered on the sheet. We spend a long time looking for it to no avail, with Tommy muttering 'like looking for a needle in a haystack', before eventually approaching a member of staff, who is standing with his back to us. *(The young man is wearing a dark green fleece which has the chapel logo on the front, but from behind there is nothing obvious to suggest that he is staff. I 'know' that he is staff, but am thinking for the first time about 'how' I know this, and more importantly how Tommy knows this, and am struck by the current cultural significance of the 'casual uniform'. It's like looking at the world with a fresh pair of eyes).*

When Tommy is standing directly behind the staff member he says 'excuse me son, we're looking for the apprentice's head, but we cannae seem to find it'. The staff member turns, pulls a laser pointer from his jeans pocket and says 'that's it up there,' as he highlights the apprentice's head high up in a corner of the chapel, marking out the scar where the hammer struck with the green circular dot of the laser. Initially Tommy seems more interested in the pointer and says 'Jeez son, what a great wee gadget that is'. He wants to know if I 'have one of them' and I tell him that I've used one when giving a presentation, but 'don't have one of my very own'. Tommy asks 'would you like one?' and I say 'not especially, would you?' In response Tommy tells me that 'you've got to keep up with the new technology, you cannae be looking like an old fool all the time'. Tommy then reads the text describing the carving from the information sheet again, partly to himself, but saying the odd word out loud, and concludes with the words 'struck head'.

Tommy then looks up, turns to me and asks me 'did you see that thing on the telly where the vicar was telling his wee boy that he had dementia?' *I'm slightly taken aback by this second, seemingly unprompted reference to 'dementia' (named as such) in a short space of time— this is not like the Tommy I know.* I say that I didn't, and he goes on to say, 'it's one of those shows that Grace always watches, on all the damn time. I cannae stand it'. I am frantically trying to think of a soap with a vicar in it when Tommy sings 'doo doo doo doo' (instantly recognisable as the first line of the Emmerdale theme tune). I say 'oh, Emmerdale' and Tommy says 'aye, that's it, bloody Emmerdale. *[There is no one no one close by, so I quickly pull my audio recorder out of my jacket pocket and place it on a ledge between us, before Tommy goes on]*.

T: I thought that was good, you know. The wee boy said 'daddy, what's wrong with you?' and he just said 'there's a wire broken in my head' and the wee boy asked him 'will they be able to fix it?' and he says 'no, not very well'. I thought that was good – aye, good.

K: Mmmmm. Oh, yeah. D'you mean you thought the explanation was good – the broken wire? *(I now realise that Tommy's reference to dementia **was** prompted, but by the apprentice's 'broken head' rather than by me, and am intrigued by this)*

T: Aye, you can... and well, just coming out with it and telling the bairn like that.

K: Being right upfront about it?

T: Aye, a, a wire broken in my head, makes..., doesn't sound...

K: Yes?

T: Not.... too terrible

K: Not too terrible?

T: Just a wire broken in my head *(I note he says 'just' – it's one of my watchwords)*

K: Sure. Sure. I remember you told me before you thought a lot of people were frightened of it, of dementia?

K: Aye, I did that

K: So, d'you think that sort of explanation, you know, on the telly, could maybe... well, lessen the fear?

T: Maybe, maybe (*sounds doubtful*)

K: But?

T: Well, no really, no.

K: Oh?

T: Och, he's getting awfy worse. Much worse than me, I tell you. And he's no an old duffer like me. And quite quick mind. Right quick. Didnae know his wife the other night. One minute she goes up stairs, next thing she comes back down and he doesnae remember.

K: Oh? He didn't rememberhis wife?

T: Didnae know she was his wife. That daft woman he married before, and she's still in her wedding dress. You know, yon one with the whiney voice?

K: Sorry Tommy, I haven't watched it in years, but maybe I should

T: Grace was in tears

K: Oh really? Oh, Tommy. So, did you talk about it ... with Grace? (*I have a mental image of Grace in tears watching the programme and Tommy just looking at her. I have not managed to keep the emotion I feel from creeping into my voice*)

T: Nae, nae hen. Nae. She's hooked on it mind. I cannae stand it. And that ugly looking woman he used to go with marrying them, you know, her, what's her name? The lady vicar with the hair hinging like a pair of old curtains, looks like a dug ... och, it's a load of rubbish

K: It sounds very complicated

T: No, it's just rubbish

K: But... but you liked, you liked... the explanation, about the broken wire?

T: Oh aye

K: So, d'you think the programme makers ... maybe spoiled that – by having too much other stuff going on, withthe lady vicar and the wedding dress?

T: Well.....Aye, maybe, maybe (*sounds plausible*)

K: Maybe... maybe it's a bit, bit like in here – you know, there are so many carvings that you can miss some of the details. I mean we even missed the apprentice's head. Cos, it's alla bit much?

T: Well, that's a right good way of putting it... Aye, right good. I cannae stand it though. Cannae stand it.

K: Emmerdale?

T: Bloody Emmerdale.

At this point another member of staff begins a talk charting the history of the chapel using a mic and everyone inside, as if programmed to respond to this cue, starts to move towards the central seating area. I ask Tommy if he wants to take a seat, and he points to the seats at the side. I pop my recorder back in my jacket pocket and we move to the side, sit down and listen to the talk, which lasts about 15 minutes. Tommy loves history and at first he sits forward, listening intently. However, the presenter has a very heavy French accent, is highly animated and talks very quickly. The acoustics are tricky and I find it quite hard to make out some of what she is saying. I see Tommy fiddling with his hearing aid. He looks utterly dejected and is looking at his feet. I lean over and quietly ask if he wants to move on, but he shakes his head. When she finishes I ask him if he could understand her accent and he says 'no, not a damned word'. I say 'me neither' and he smiles. We get up and continue to make our way round the chapel, looking at various carvings of fallen angels, angels with bagpipes and my particular favourite, the 'green men'.

Hot under the collar

A little later we are standing at the opposite side of the chapel looking at the laminated sheet together and checking how many of the featured carvings we have seen (we have been looking at the carvings in order of interest to Tommy, rather than sequentially). We start with number one on the sheet, both saying in unison 'seen that', 'number two, seen that' etc. This seems to trigger something in Tommy's mind as he says to me, '14, 14, that was my number'. I ask 'your number, when was that?' and he replies 'at the Murray Club'. (I know from our previous meetings that the Murray Club is a men's group run by a former minister at Tommy's Church that he particularly enjoys). I have no idea what he means by '14 was my number'. I wait, but as he doesn't say anything more on this I say 'you've told me that you really enjoy the Murray Club, but I didn't know you had a number'. He then tells me a story that I struggle to follow, but it involved 'a sheet, a bit like this one' (the laminated sheet) and 'everyone had a different number, 13, 14, 15'. Tommy's number was 14. I ask if it was a quiz, but he says no. I can't work out if everyone was given a different number early in the evening, or had to work something out on the sheet, but I get a clearer sense that the discussion had then moved on. Steve, the former minister had said to Tommy just to write his number on the back of the sheet, but he couldn't (*I assume because it was a laminated sheet*). Tommy goes on to say that he just kept saying it to himself '14, 14, 14'. He goes on to say 'I was getting right hot under the collar about it', but then when it came to his 'turn', he 'just said it out loud, you know, 's'if I was sure - 14' and after that, he tells me that he felt 'a lot more... confident'.

Tommy looks rather pleased with himself when he concludes. I still have no idea what the sheet was, or what the exercise was, but I reckon that this doesn't matter and the key things to focus on are Tommy's emotions – 'getting hot under the collar' and then feeling 'more confident'. I don't want to undermine his sense of satisfaction by letting him know that I haven't understood *what* he's pleased about. I go on to say 'that was great Tommy, you know, that you managed that, but when you say you were getting hot under the collar, what were you worried about?' Tommy tells me, as if stating the obvious, 'looking stupid'. (*There it is again –this fear*). I then say, 'so the fact that you remembered your number, that made you feel a lot more confident that....' and Tommy says 'I can keep going'. *So there we have it*. I find myself saying 'I know how much you enjoy it and, from some of the

laughs you've told me about, I bet the other men really enjoy your company too – whether you remember you're number 14 or not'.

Trying it on for size – Concepts of time

As soon as I say these words I realise I could be in danger of crossing a line because 'I' don't want Tommy to stop going to a club that he enjoys. So far he's coming up with his own solutions. So far. What's the 'right' thing to do? I could point out all the things that he can do. Or that Steve seems to know about his condition, seems willing to help him out. I'm not sure. So I decide to pull back and just leave that seed of thought with him. I am struck by the contrast between Tommy's desire to keep things from the men at the Murray Club and his willingness to tell Mike about his Alzheimer's in such a casual way when buying his admission ticket. I realise also that he now keeps introducing Alzheimer's into his conversations with me, actually today there is no keeping it out, whereas previously it was kept more in the background – he'd talk about the diagnosis or the side-effects of the medication, but not the condition itself. His thinking is shifting. I wonder if by telling Mike, someone unknown to him, he is testing the water, 'trying it on for size'. I am reminded of a Journal Article on GPs thoughts on the 'timeliness' of a diagnosis of dementia, which spoke about the slow unfolding of becoming a person with dementia. In Tommy's case this unfolding is happening before my eyes. The article referred to the Greeks having two different forms of time –the familiar 'chronos' and 'kairos' - which is concerned with there being an opportune or right time; the latter being more in keeping with GPs understandings of 'timely' than 'early'. I sense Tommy has his own timetable. He is finding his own 'right times'.

Looking out for the danger signs: Pride comes before a fall

(I am aware that my last exchange with Tommy was an important one, but I have had to rely on my own memory store to record the details. There is no one else in the part of the chapel that we are walking round, so I retrieve my recorder from my pocket and hold it discreetly inside my right hand). At one point I am stepping back to look up at a carving of the seven deadly sins. There is a steep stairwell leading down to the crypt a few feet behind me. Tommy says to me 'mind you didnae step too far back, or you'll be down that stair, and you might no be as lucky as yon stupid American woman'. I say 'thanks Tommy, if I fell down those stairs I'd be a goner'. I then add 'Looks like you're my minder today'. *(I had actually forgotten about the stairs and although I am a good few feet away from them, am touched that Tommy is looking out for me. I am also struck that he has effortlessly remembered what, to me, seemed like a fairly 'insignificant' detail about the American lady falling while taking a photograph, yet has been having real difficulties remembering other 'significant' things, such as meeting arrangements, or the seemingly crucial 'number 14').* Tommy says 'first thing I did when we came in was look out for the danger signs, says to myself you better mind that Tommy, and you better mind that'. I ask if that's something he's always done or learned to do more recently and he says 'just common sense, pride comes before a fall, pride comes before a fall.' We both laugh at his quick wittedness.

Taking care of the needy and enforced voting habits

We move from the seven deadly sins to the seven corporeal acts of mercy ('a right bloody mouthful', in Tommy's words), the first of which is 'taking care of the needy.' When I read this out from the information card below the carving Tommy jokes with me:

T: Well, it cannae be that Osbourne fellow

K: (laughs) Spot on, I didn't know you were into politics Tommy (*this is the first time he's mentioned anything remotely political - I suppose Tommy has taken me by surprise*)

T: No really, but his ugly mug is never off the news

K: You're right there

T: You'll be a Tory voter, won't you'?

K: Are you kidding me?

T: (Shakes his head)

K: No, no, I'm no fan of the Tories, Tommy (*very indignant*)

T: Oh, I thought all the clever folk voted for them

K: I'm not sure I'm all that clever Tommy, but what makes you think that all the clever folk vote for them anyway?

T: I... was ... when I first got the vote, you heard of Home? (*Pronounced Hume*)

K: Sir Alec-Douglas? Yes, I used to get dragged round the Hirsell by my gran in the Easter holidays

T: Aye, so you'll know he was the landowner. And a Tory.

K: Mmmm

T: A right clever man, you know, educated, Oxford and that, and he told us that we had to vote Tory or we would be out of a job. So you did as you were told.

K: Seriously? Like a threat?

T: Oh aye, I didnae really know enough about it all to be truthful. But I needed a job. I've always voted for them. Just habit really.

K: Still?

T: Aye

K: But (*Wondering whether to pursue this*)...but you said Osbourne's not one for helping the needy?

T: Cannae stand the man

K: So, so, why do you still vote for them ...now?

T: Just do. Mind, they seem to be a damn site better at, you know... thingying the books

K: Cooking?

T: (Laughs) No, no hen, you know what I mean.

K: (Laughs) Sure. Reducing the deficit (*in posh voice*). Would you ever think about voting differently'?

T: What, like for her with the pair of legs like a thingamy..., clomping about in her big shoes like Minnie Mouse? I don't think so. No, no, I'm a Tory voter, just stick to what you know.

K: Fair enough, we'll agree to disagree as they say.

T: (Laughs) As they say. I hope I havenae offended you hen.

K: Not at all Tommy. No, I'm fascinated.

Taking care of the dead: straightening nails, straightening bodies

We continue looking at the carving of the seven corporeal works of mercy. *I am still bemused by Tommy's revelations about his lifelong voting habits, but then my attention is caught by the last act of mercy, which is 'taking care of the dead' and depicts two people placing a body in a cask. This part of the carving has a particular poignancy for me as I had attended the funeral of one of my husband's lifelong friends the day before. He had died suddenly, suffering a massive heart attack at home alone while his partner was out with her friends. The service, led by a humanist celebrant, was both heart-warming and heart breaking, and I must go deep into thought.*

Tommy picks up on my apparent interest in this carving and I become aware that he is looking at me quite intently. After a moment he asks me if he's told me about the time he worked with the undertaker when he was a boy, and I shake my head. (*The seven works are all captured in the same carving, so I am not sure how Tommy knows it is the last one that I have been thinking about ~ a coincidence? However, I am struck that the carvings are serving the same 'memory prompting functions' for both of us*). He goes on with his story:

T: Was the year after the war broke out, I got a job with the undertaker, Bill, straightening out old nails, you know, cos new nails were guy hard to come by at that time. What, with the war and all.

K: Sure.

T: I was nine. I'd been, well, helping out for oh, a few weeks, when he gets word to go and collect a body from one of the farms up by, and asks me come with. Turns out the farmer had gone out in the morning with his horse, up to, to plough the field and must have dropped dead halfway down the first furrow. That horse! Phew. Just carried on going up and down the field, up and down, up and down, and so nobody knows the farmer's died 'til the horse came back to the stables at 5 o'clock without him.

K: Amazing.

T: Because the farmer's been dead for so long, the rigor had set in and he was stiff as a board. But his arms were (demonstrates arms straight out in front of him as if still pushing the plough). So old Bill's gonna have to... to snap them, like to get him into the... box, you

know, one he keeps in the van for taking the bodies back to his. That's why he's asked me along.

K: Oh?

T: I gets the job of taking the farmer's wife for a long walk. Tells me to take her, well there's a great big oak tree down by the stream (pointing into the distance) and he says head down there. Should be far enough away that she willnae hear, you know, his arms cracking.

K: Oh God!

T: But the poor woman's sobbing that hard, and I'm only nine mind. Just a laddie. She could hardly put one foot in front of the other, poor soul, so we didnae get very far. Oh, she heard the cracks alright.

K: *[I am transfixed and when he tells me about the cracking noise, I instinctively put my hand over my mouth.]*

T: Aye, then after old Bill's got the farmer in the back of the van, poor woman's still in shock. Couldnae just leave her, so Bill says we need to take her, well it was her sister's house, which was a fair distance away mind. So she's in the front of the van with Bill and I, I has to go in the back, sit on top of the box, you know, with the farmer's body inside, all broken and... all the way to the sister's. After that I never went back. No more ...nail straightening.

Often Tommy's stories start midway through and he jumps about a bit, but this story is told fluently and has an obvious start and end point. When I look at him as he is telling it, I have a sense that he is replaying the scene.

I am horrified. Tommy catches my expression.

T: You'll have the hankies out next.

K: Sorry Tommy, I'm a bit lost for words. That must have been such a traumatic experience for anyone, let alone, what a nine year old boy? I'm not surprised you never went back.... You seemed, I don't know, to be reliving it there. God, that was shocking Tommy, really shocking, it must have really affected you.

T: Aye, you're right there. Had a thing about them since. Och, I know I'll end up in one, no fear of that, but I have a horror of lying for hours 'fore anybody finds me.

[Tommy has told me before that he has a strong faith and has no fear of dying, but the main reason that I don't probe any further is that I am a bit thrown by his story, and also still puzzling over the fluency of his narration].

On the way out Tommy asks me if I'm going to sign the visitors' book and I say 'do you want to?' he says 'you sign it for both of us.' I ask 'with your pseudonym?' and he laughs loudly, shakes his head and says 'James Bond'. *(I don't actually think anything about this at the time).*

Forgotten skills, forgotten wives

T: I'm going to get a book like that

K: A visitor's book?

T: No, just like that, with lines in. I'm gonna start writing again.

K: Are you? (*Surprised*) What sort of thing are you going to write about?

T: I'm a bit worried about going back to tell you the truth.

K: Going back... to writing?

T: To the dentist.

K: Oh?

T: I was there last week and it was a new one again. Third new one we've had. First that Greek fella that Grace fancied (*I have heard all about him!*), then the Polish woman. Now one of these women from Africa. What do you call them, with the thing they wear? You know, on their heads?

K: A Muslim?

T: Aye, so you cannae see their faces.

K: Is that why you're worried about going back to the dentist? Because you can't see her face? (*I am thinking Tommy has maybe done what I call 'jumped tracks' – this is something he seems to do quite often when telling stories*)

T: No hen, I could see her face alright. She didnae have the full thing, with the wee... (Makes gesture of a slit across his eyes). No, she was very nice. I made her laugh. Grace was giving me the look.

K: I'm sure you made her laugh Tommy. You make everyone laugh. It's a real gift. But, but what is it that's, well, worrying you, about going back?

T: I don't want to have to say I cannae... I cannae do it again.

K: Did something happen at the dentist Tommy? (*I am now stitching what I thought were two separate stories together in my mind. I think I know what he is going to say, but don't want to ask directly in case I'm wrong*)

T: They asked me, you know, to thingyme the form, and I couldnae do it. I couldnae write my own name. I was just....blank.

K: Oh, I see. So, you want to buy a book - to practice writing your signature at home?

T: Aye, like when I had my stutter. At school. I've told you. When I was the black sheep and they couldnae teach me anything. Not a damn thing. I just kept at it – saying my name, over and over 'til I could do it ... without, without stuttering. I'm going to do it again. Start writing again. (Says his full name three times and makes a writing gesture in the air). But I need to buy a book first.

K: Sure, sure. A book ... with lines. Yes. (*Faltering: I am aware that I am treading water here. This strikes a painful chord. I am remembering the first time my grandad couldn't remember how to write his signature. So this is the down side of these 'moments in the present'*)

triggering 'memories from the past'. I am not immune to them either. I am saying to myself get back to the present Karen, come on, back to the present. This is a big, big thing Tommy is telling you. He needs your undivided attention).

K: I know you've told me before that you've always found writing a bit tricky. Was this different? *(He has told me he found it hard at school and also found it a bit tricky when he signed the consent form for the study, but he did manage).*

T: Aye, I couldnae do it. Then same thing at the Murray club *(I suddenly realise that when he told me he couldn't write the number 14 on the sheet at the Murray Club, he meant he literally couldn't write it – and I missed it, completely missed it!!)*

K: And you're worrying about this Tommy?

T: It gave me a start. A right bloody start. Just hit me. You know. So, this is what it's going to be like. One day it's how to write my name. Next ...

K: Yes?

T: Next minute... (Shrugs)

K: Oh Tommy, that's a pretty big thing to be carrying around with you. Have you talked to anyone about it? About the future? There are people who are really skilled in helping with things like this. If you are worrying about it, it might help?

T: No hen, no. I'm going to get worse. I know I'm going to get worse. But I'm trying no to worry about it too much. Just don't want to look like an old fool next time I go.

K: I know. Of course.

T: No point worrying about things you cannae do anything about. Best just trying to forget about it - and that shouldnae be difficult (laughs).

K: Tommy! You said Grace was with you, at the dentist?

T: Aye, gave her a start and all. But then she says writing's never been my strong suit. There's plenty things I still can do. Plenty. Chuckles.

K: That's certainly true. Like making everyone you meet laugh for one. And stopping daft women like me falling down the stairs for another.

T: (Laughs) Aye there's that.

K: So, you'd rather focus on the things you can do?

T: Doesn't everyone?

K: I think they probably should, but it's not in everyone's nature.

T: Maybe not. No point though. One day at a time, I say

K: One day at a time (lifts water glass)

T: Aye (clinks glass)

[Long Pause]

K: So, is there much going on at your church in the run up to Easter? (*Seems I've decided it's time to change the subject – rather than waiting for Tommy to steer the conversation – a sign of my discomfort?*)

T: Aye, stuff on every night. All the different churches get together, take it turnabout. It's our turn tonight.

K: And are you going?

T: Of course.

K: Will there be many there?

T: No, no. Less than 20 last night, maybe only 15... Not sure what time it all starts.

K: I guess we should be getting back up the road, before Grace starts thinking I've abducted you

T: She'll be glad of the peace hen. I think I'll get one of those books though.

K: With the lines?

T: Well, that, but one about the chapel. That they had at the desk.

K: That's a nice idea. After you.

T: I'll nip into the gents first – this bladder again

K: I'll nip into the ladies too then.

I switch off the recorder, put it in my pocket and we make our way across to the toilets.

Identity crisis

I nip into the ladies, aware that I am trying to go at speed and get back into the foyer before Tommy. I am not sure of the details of the latest 'mix-ups' that Grace has referred to, but I don't want one to happen 'on my watch' – and this is what I find I am thinking – 'on my watch'!

When I come out into the foyer there is no sign of Tommy and I loiter for a bit. When he comes out of the gents he says to me 'my, I didnae know I was so old and ugly. I looks in the mirror and thought, who's that funny looking old bloke?' I say 'must be the lighting in there, you look just dapper to me'. However, I am also remembering the story that Grace told me during our initial meeting about Tommy going up to one of the mirrors in the hallway of a hotel, having become a bit disoriented after coming out of the gents. Apparently he had asked his reflection (another funny looking old bloke) if he knew the way out. She concluded by saying 'I thought, oh my, we're a bit further down the road than I thought'.

We head back over to the desk and Tommy buys a copy of the book about the Chapel. He enters his pin without hesitation. *I am trying to come to terms with Tommy's 'identity crisis.'* *I am struggling to reconcile his inability to write his signature and apparent difficulty recognising his own reflection with his retained humour, quick witted ability to deal with the*

payment scenario in the café, and recollection of little conversational details such as the American woman falling over taking a photograph. I realise once again the limitations of the 'stages model' of dementia. Tommy is chatting away to Mike about his visit, joking, something about what'll happen to him if he tells folk he 'spent the morning looking at little green men', completely oblivious that the chap in the queue behind him is shifting about impatiently. I find myself welling up. Oh Tommy - one day at a time!

Real mints or Captain's mints?

We head outside and make our way back to the bus stop. As we are walking back up the road I take a packet of mints out of my bag and say to Tommy 'would you like a mint? Refuse nothing but blows?' Tommy laughs and asks 'is it a real mint hen, or a captain's mint'. I tell him I don't know what a captain's mint is and another story ensues.

Tommy tells me that when he way away with the church (I already know that he and Grace go to an annual retreat with a large group from his Church) they were staying on the caravan park and there were rows and rows of caravans that 'all looked the ruddy same'. At some point he must have gone off site on his own and then when he headed back to the caravan park he couldn't find his own caravan. 'Up and down, up and down. No idea how long I was wandering about'. Eventually Grace started to get anxious that he hadn't returned and 'the Captain' (a character who features regularly in Tommy's stories) set off to look for him. Eventually he found Tommy and he says 'there you are, what are you playing at, there's something not right with you, not right at all'. Then when they got back to their own house a few days later, the Captain came to the door and handed Tommy 'a nice wee tin of peppermints, you know the kind, for what I've got'. I say 'oh, the senior moments mints, for memory loss?' and Tommy says 'aye, that's them, but I call them the Captain's mints'. Tommy goes on to tell me that Grace came to the door and the Captain said to her 'But I think he needs something more than these. There's something not right with him' and Grace said 'you don't need to tell me there's something not right. I have to live with it'.

I am slightly outraged by the Captain's behaviour. I met him once while out walking with Tommy and found him very direct then too. I ask Tommy 'how did you feel about that?' He replies 'he was trying to help'. I then ask how Grace felt about it and Tommy tells me that she just laughed. 'Thought it was, well kind of him I suppose, you know, that he'd gone out and bought the wee tin specially'. He adds that 'when the Captain's wife found out though, she was livid, absolutely livid with him'. I find myself saying (rather unguardedly) that I'm not surprised. Tommy says, 'no hen, he means well, he means well'. I then ask Tommy if this was recently, since he's had his diagnosis, and he tells me no, no lass, it was before that, oh, quite a bit before that.

A twist in the tale

As we carry on walking I am thinking, well this is a twist in the tale. Up until now Tommy has been quite adamant that he would never have known anything about his Alzheimer's if he hadn't gone to his GP with his shoulder and failed the 'four crosses' test. He has told me numerous times that he would have been 'none the wiser'. I am thinking about the study design and the length of engagement. I am not sure if Tommy is disclosing more information to me because he trusts me more (I am now his wee sister rather than a floosy after his money) or if this is an indication that he is processing the information about his

condition, pulling in threads from the past, and the narrative is being reconstructed as he is coming to terms with it more. It is also becoming tighter – the stories of his past that all ran into each other have ceased. Or maybe a bit of both. Or maybe he is simply mistaken about the timing of the ‘Captain’s mints’. I certainly have formed a very different picture today than during my previous meetings with Tommy. I am aware that I only have the wrap up meeting left. I am captivated by his story and I really don’t want to put it down.

Next Steps

As if reading my mind, Tommy asks ‘so have I filled up another few pages of that book of yours?’ I say, ‘you most certainly have’. He then says ‘there’s plenty more’. I recognise this as an opportunity to revisit the study terms and say light-heartedly ‘I think I’m probably already over the number of words that I’m allowed to use, honestly, you’ve given me so much Tommy. I then remind him of the ‘wee yellow leaflet’ and that it talks about us meeting up to seven times in total. When I ask ‘would you be happy to meet with me once last time to go through it all, and to thank him and Grace?’ Tommy replies that he’s happy to keep meeting for as long as it’s useful to me and adds ‘you best speak to my secretary’. I confirm that I will do, adding that I’ll give her a phone once he is on the bus. I then say maybe we should leave it a wee bit longer ‘til we meet up, rather than ‘rushing over the finish line’. Tommy thinks about this and then says well, we’ve got Tam the Bam for the next couple of weeks (a friend’s dog that they look after from time to time), so that’s maybe not a bad idea. He then says ‘it’s fair given me a boost, I’m right glad I’ve met you, I tell you. Right glad.’

While we wait at the bus stop we chat about the dog and how much Tommy is looking forward to having him stay. The bus arrives, I thank him again, confirm that I’ll let Grace know that he’s on the bus and will fix up a date with her for our next meeting. He waves as the bus drives off and I wave back.

I get into my car parked up the road and phone Grace to let her know that Tommy’s now on his way home. She says ‘you’ll be ready for a lie down’ and laughs. I say ‘not at, all’ and I tell her how much I enjoyed it, adding that I think Tommy did too. Grace says ‘oh, he’ll be full of it. He always is after he’s seen you’. She asks me if we managed to get a bite of lunch, and I confirm that he had soup and a roll, adding ‘but the soup wasn’t as good as your own’. I then ask Grace if she is still okay for me to meet up one final time, just to wrap up and thank them. I add that Tommy seemed to be up for it, but I am aware that she’s been feeling tired and to please say if it’s too much. She says no, no, she’s very happy about that. I stress that the meetings with Tommy and with her have been extremely useful, and can’t thank them both enough. I then say that I thought I should maybe leave a bit of a longer gap ‘til the final meeting, and know that they have the dog for a few weeks any way. I leave it that I will call in a couple of weeks to fix up a date maybe a couple of weeks after that.

As soon as I come off the phone to Grace, I pull my recorder from my pocket. I push my seat back, put my seat into the recline position, shut my eyes and replay the visit, scene by scene, trying to ‘brain dump’ as many of the details as I can.

Appendix XIII: Selection of Reflexive Journal Entries



Wading through the theoretical literature: Where's the 'Fun' gone? [February 2014]

I keep a photograph of a painting beside by desk at home as a reminder of the importance of asking the right questions. I came across it several years ago while supporting a digital storytelling project at the SSBA centre in Cumbernauld. [This experience also taught me that there is an art to making things happen – I had a meeting the same day at an NHS hospital about a similar initiative – by the time a meeting with the various powers that be was set up to approve the project, the SSBA had already held an 'OSCAR ceremony'].

While working at SSBA I asked about their fantastic outdoor adventure playground and was told – 'there's a story behind that'. Having secured funding to build the playground, they wanted to make sure that they got it right and the first thing they did was consult the experts. This revealed that the top 3 things that children with physical disabilities enjoyed were water, sand and swings. This was followed up by a discussion group with children who attended the centre – which asked what they most enjoyed doing when they went to a play area, and with some minor variations, this pretty much confirmed the experts' views. However, an art worker at the centre then said 'you're asking the wrong question – you've literally got a blank sheet of paper here' and she asked the children to draw a picture or write a story about what they'd really like to be able to do when they go out to play. Those with siblings generally wanted to be able to play on the same equipment as their (able-bodied) brothers or sisters, but the runaway top answer was:

"We want to go up high".

With a little imagination, the aspirations were accommodated.

I've been drawn to this painting a lot over the last few weeks and asking what it's trying to tell me – beyond 'you need to ask the right question'. There was undoubtedly a greater

degree of risk involved in meeting the children's aspirations – but their aspirations were respected – presumably because their reasoning was 'deemed to be sound' – and the solution was affordable. The children were unable to go up high, but 'technologies' could be developed to compensate for the physical impairments – modifying the environment consistent with the social disability model. There was a genuine opportunity for them to be and do the things they valued, and which were socially valued. So I'm thinking capabilities. The art worker's question opened up new possibilities by giving the permission to think beyond adaptive preferences. And these were actualised

This is all well and good – but I think what it's trying to tell, what it's **really** trying to tell me is that what's missing in the sociological and philosophical texts that I am reading is the place of creative imagination, senses, emotions, dreams and pleasure

So I'm wondering: Where has the fun gone? Surely there has to be a little room for enjoyment too?

Is this pointing me to Martha Nussbaum? Is capabilities thinking going to be my theoretical lens?

A chance encounter with a music professor – A classic case of misrecognition? [October 2014]

On Friday I took my mother-in-law to an appointment with her cardiologist and while sitting in the waiting area I struck up a conversation with a delightful and rather outlandishly dressed older lady who was in 'to see about these cataracts'. She mentioned problems with her 'music glasses' and when I asked if music played a big part in her life, a story unfolded. She was a professor of music and had worked for 56 years at the Music Academy in a nearby town ('or the conservatoire as they are now calling it – there, of all places!'). She had been planning on retiring in June anyway (she travelled from Edinburgh by train and had reduced her working hours to one day a week when she turned 75). However, 3 weeks previously she had received a letter in the post telling her that she was 'no longer fit to teach'. The reasons for this assessment were attributed to her 'increasing forgetfulness' – and she relayed a catalogue of incidents involving losing a handbag (I was distracted by excitement of seeing a former student), making an undue fuss and being overwhelmed by its loss (it held everything I depend on), getting on the wrong train and stepping out in front of a car (both because I couldn't see) and finally arriving for a concert at 8p.m. rather than 8 a.m. (I ask, who holds a concert at 8 in the morning?).

Her distress centred on being informed of this decision by post and crucially having her ability to teach called into question. She said that her confidence had been damaged beyond repair, adding that 'they said I was welcome to continue to attend the Friday concerts – they are terribly good and free – but felt I should have a chaperone. A chaperone! I've been making the same journey for 56 years. I could do it in my sleep'. When I asked if she would continue to attend the concerts, she answered that she was undecided, adding 'it's the one place where one can still be someone and that's terribly important. But having been discredited, I rather think it may take the pleasure out of it'. Before she left I reminded her of the excitement she'd described on seeing her former student, told her how delightful I'd found her company, hoped things went well with her cataract operation and suggested not being too hasty in reaching *her* decision. When I

shared the story with my mother-in-law she said 'well let's hope she doesn't step out in front a train'.

Afterwards, I started thinking about the loss of cultural capital and how this could result in a loss of social capital, so I guess in I'm Bourdieu mode just now. The lady was obviously very 'well heeled' and economic capital didn't seem to feature. Was the letter an act of symbolic violence? Was I at risk of seeing symbolic violence everywhere? But then I started thinking about those other elements in the story – that word '*pleasure*' and then the '*excitement*' of seeing someone whose life she'd contributed to – this rather than impaired memory serving as the explanation for 'forgetting' about her handbag. So I'm still on that bandwagon. But then the handbag – it contained everything she *depended* on. What life props were inside: money, keys, train tickets, her 'music glasses', a phone, a diary? How much do our everyday lives depend upon these things? Do they matter more or less when memory starts to fail? At what point do they cease to matter? What does this symbolise? Or was it simply the case that her understandable behaviour was attributed to her 'condition'?

I think I may be on the long road back to where I started – retracing the course of recognition.

Reflection on what lies within the domain of the possible [27th March 2015]

Janelle Taylor asks:

Why is it apparently so difficult for people to "recognise"—as a friend, as a person, as even being alive—someone who, because of dementia, can no longer keep names straight? How does the turning away of friends, at the level of personal networks, relate to processes of "social death," social exclusion, and abandonment of people with dementia on a broader level? In short, how do questions about "recognition" in its narrowly cognitive sense get implicated in the "politics of recognition" on a broader scale?

She says: 'my mother's decline has been very slow and gentle, and she has remained good tempered and affectionate throughout....Even though my Mom is seriously impaired she is still sweet, cheerful, and sociable. I enjoy her company. Many other families are far less fortunate in their experience of dementia, and for them perhaps the gothic and zombie stories do resonate. But my experience with my mother's dementia is no "horror story" — and **this, too, lies within the domain of the possible**'.

And it IS possible. Over the last year, Rachel, who has been my faithful fun-loving friend since my very first day at school, has **shown me that it is quite possible to hold the story of a loved one until death**. And today, having never spoken in public in her life, she chose the convent care home where her dad lived his final chapter to make her debut. She had given me a clue that she might say something when we went to hear Sally Magnusson talking about her mother's experience of dementia some time ago, but I wasn't sure if she would be able to go through with it. Walking to the front of the packed chapel, she calmly told those who had gathered to mark her dad's life and passing that his quality of life was not poor. He continued to have a role within the family, always joining in the family celebrations, even if that meant her husband and son had to carry him unceremoniously from the car, up the path and over the threshold, seating him at his usual place at the table and indulging his passion for peppermint creams. Hats off.

Tommy: The Poet Who Doesn't Know It [February 2016]

Looking through the transcripts from my last outing with Tommy, I am struck by the poetic quality to his talk. I'm not sure where this fits in with the study aims, if at all, but for a man who was 'put in with the useless lot', I can't help thinking I should do something with it. I'm pulling out a few extracts for safe keeping!

*We could go for a walk cos they've said that
I'm needing to burn off the fat
They've put me back on the 5s,
I couldnae cope with the 10s
I mean it says on the packet that
They give you cramps and upset your sleep
And can make you need to pee
But, och I tell you hen
The wife's that disappointed in me*

*When I wake up
In the wee small hours
That's when my mind starts reeling
I daren't wake the wife
So I just lie there, stock still
Counting the dots on the ceiling*

In the field and getting all caught up in the unfolding story:

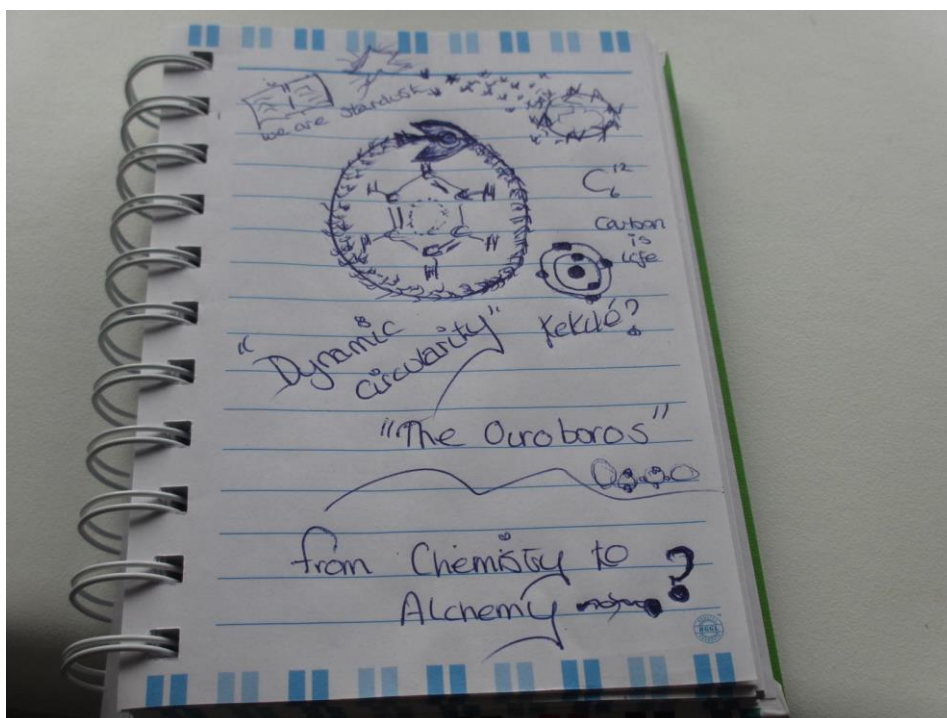
Temporality is critical [February 2016]

More by accident than purposeful design, my methodology has ending up combining different types of narrative. I planned to engage with the concept of 'enacted narratives', the little mini-stories or self-contained episodes that make up the stuff of the flow of people's everyday lives. In so doing however I have also been treated to constructions of the participants' life stories (or selected extracts from across the life course). Finally, although not intended to be a longitudinal study, I have become part of the unfolding narrative of people's lives as I meet with them over several months. For me, the purpose of repeated meetings with each participant was to engage in different everyday activities, both routine and those with more cultural significance, potentially with different people and in different settings, in order add breadth and depth. I recognised implicitly that this might result in encountering change and continuity over the duration of the study, but it was not a core focus. I had not anticipated getting caught up in (or possibly shaping) the unfolding stories of people's lives.

'Context' has always been central to my research. I set out with an aspiration to locate the experience of living with dementia within a broader socio-political and cultural context. It has become apparent that 'contexts' matter at two levels: the immediate contexts in and through which people enact their daily lives and the changing contexts that form the 'backdrop' of their biographies. Time (or temporality) has emerged as critical.

Embracing the circle [March 2016]

I am thinking about Ricoeur's account of the dynamic circular relationship between narrative and life, inserted within the forward arrow of cosmological time. I find my attention wavering and soon I am back in my old science classroom at school – a highly unsuitable venue at the top of a winding staircase of an old building known as 'the Tower'. It is Chemistry, we are studying aromatic hydrocarbons and Mrs J is at the blackboard. She is recounting the story of Kekule's dream while on board a London omnibus. For years the structure of benzene has plagued him and then into his daydreams comes the image of a snake chasing and then swallowing its tail. Suddenly he has it, the electrons are not rigidly paired in alternating double bonds, but spinning round and round in a circle, 'dancing mockingly before his eyes'. And Mrs. J's conclusion? 'A lot of things in life make more sense if we stop thinking rigidly'. I find I have been doodling. I realise that I too have been thinking too rigidly, in phases, rather than continuously. I need to embrace the notion of dynamic circularity.



Needing to go deeper [April 2016]

By engaging with older people with dementia as they went about their everyday occupations in real-time, I expected to observe their habits and established practices, with a view to picking up on cultural clues (the individual habit is the cultural norm for the group) – [habitual or identity agency]

I also expected to observe to some of the issues they might encounter along the way, and get a sense of how they manage to negotiate and coordinate (or not) – [pragmatic agency]

There was also an expectation that in the course of carrying out these occupations people might connect with images from the past, or perhaps from the future and that these might be shared as 'small stories' about the stuff of everyday life. There was the aspiration to use these stories, again by drawing upon cultural norms, to situate people's experiences within a broader socio-cultural context.

I also had the idea that people might be less future oriented –at least in terms of making long-term plans, perhaps having different aspirations - and that this could mount a challenge to the emphasis on 'life course' style agency in policy – (based on individualist notions and the belief that human time is only meaningful if it is full of plans and goals ~ as if we might 'colonise the future']

My interest was sociological.

Things did happen pretty much as expected. It would be quite possible to give an account of the different forms of agency I encountered, how agency was enacted, and to offer a cultural reading of people's everyday occupations.

BUT....

What I found fascinating once I actually entered the field was not what the evoked images from the past or imagined future 'did' or what they contributed to in practice – but their *content* and the way in which they were 'evoked'. I came to see that towards the end of a long life, so much of the past is 'in' behaviour – people don't just have histories, they *are* their histories. What's more many of the evoked or recalled episodic autobiographical memories were described in rich detail (something that the memory testers maintain does not happen in old age, let alone in dementia). In the small acts of doing, often memories were introduced from deep in the past.

And because the memory-images were recalled or evoked 'in action', prompted by what was happening, they were often turned into small stories with dramatic structure, conveying their emotional importance. [The theory is that they are recalled for what they add to the present situation, and may also guide responses to the situation encountered, opening up new ways of perceiving it - but it not so much a capacity to imagine alternative futures for themselves that I've encountered, such that actions can be changed in thoughtful ways, but more a case of what might have been for them, which is often turned into an imagined alternative future for others....].

Sometimes the most poignant memories seem to be from a particular period in time for that person [childhood, early days of parenting, doing things with now absent friends] and are transformed into hopes or aspirations for grandchildren, 'the next generation' or the exercising of responsibility to those who have gone before.

Good old Ricoeur has quite a bit to say on this distinction in terms of 'effort' involved, drawing as always on Aristotle. As with time (chronos and Kairos), the Greeks had two words ('mneme' and 'anamnesis') to distinguish between memory as appearing passively, to the point of characterising an affection, a memory popping into mind - and memory as the object of a search ordinarily named recall, recollection. Time remains the factor common to memory as affection and memory as recollection as active search. The latter stems from our capacity for searching – the starting point remains under the control of our

explorer of the past, whether the connection that follows is the result of necessity or habit. 'The main thing is that one must know the time' – to be able to make an estimation of intervals lapsed, whereas the evoked memory requires no such capacity – the source is external. Aristotle presents the first analytical description of the mnemonic phenomenon of recollection, which is contrasted with the simple evocation of a memory that comes to mind. The richness and subtlety of his description puts him at the head of a wide range of schools of thought seeking a model of interpretation for modes of connections arising from 'necessity; or from 'habit'

And these memories didn't all come at once – I began to make connections between specific events and the whole story in true hermeneutic fashion – it has reaffirmed the connectedness of human experience. And when people remembered a particular episode – they tended to recall the whole situation – 'bounded' as a distinct episode. *Thinking and acting in the present are related [connected] to situations separated by space and time*

Thoughts of the future very much endorsed Wray's (2004) gerontological concept of agency as relational, creative and generative. Temporal and relational connectedness is very strong in the data, there is almost a responsibility to the past and to the future [for H a greater connection to those who have gone before and A & J those who are yet to come] – Schutz [predecessors, contemporaries, successors]

Sense that although temporal orientation is impaired [or reduced] with dementia – [e.g. none of the participants would pass the day, date, year test] in some respects the participants (at this early stage) all displayed a more expansive sense or experience of time.

These emergent stories are primarily about continued citizenship – in many different ways and in accordance with people's own local cultures, challenging negative stereotypes. There is something also about the different nature of family inputs, but what is really leaping out is that the biggest changes and threats to occupations have been shaped by other dementia-unrelated and 'bigger' things in life. I think my conclusion is the obvious – if you look for deficits or ways of coping with adversity, there's plenty to see, but if you put dementia to one side, there is a 'much richer' and more nuanced picture.

Coming up for Air..... [13th May 2015]

The Limits of Temporality: Reflection on Unfaithful Music and Disappearing Ink

So, I have just finished reading this book and I am in tears. I 'fell in love' with the bespectacled musician within seconds of his first appearance on Top of the Pops in 1977 in the way that only a 13 year old girl can. But the love endured. His music has provided the sound track to the highs and lows of my own life story ever since. Ten years and one day older than me, once upon a time I truly believed that our biorhythms were synchronised, with each new album giving voice to my dominant emotions of the time, telling my whole life with his words so to speak, although not with his 'song' singular, but through a vast musical catalogue spanning almost forty years. A truly objective reading of this autobiography was never a possibility. But armed with my evolving understanding of narrative and its purpose, and a (semi) critical eye, I thought the construction was perfect, achieved greater coherence than a linear amble through the milestones, and made perfect

sense. It also helped me pinpoint what it was about 'Time and Narrative' that has been jarring.

Elvis's father, the late Ross MacManus left home when 'Elvis' was seven and his early memories of the man are few, yet they give structure to and somehow seem to fill the book. The autobiography begins with an account of the first time Elvis saw his dad perform with the Joe Loss orchestra at the Hammersmith Palais one Saturday afternoon (simply to give the lady who lived below a break from his flying scissor kicks during the wrestling). This fuelled his desire to perform. The book concludes with a recollection of the first time he was allowed to accompany his dad in a musical performance while still a novice guitar player, volume turned down, and the words 'everything since has been a similar trick of the light'.

In the latter third of the book comes the longest chapter, 'Putting away forbidden play things'. It is punctuated with the lyrics from 'The Puppet Has Cut Its Strings' – a song about his father's death. The chapter opens with an account of how Elvis came to compose and first perform (a rehearsal) 'The Birds Will Still Be Singing', his father's favour song, and ends with its performance at his father's funeral. In the pages in between is a heartfelt account of his dad's signs of ageing, followed by his at times harrowing battle with Lewy body dementia:

"In the waking hours, his agitation and hallucinations mounted, his eyes widening in horror as he called out for someone that none of us knew, scrabbling until his heels were raw in an attempt to escape something that none of us could see".

The book title 'Unfaithful Music and Disappearing Ink' is intriguing. I instantly recognised 'Disappearing Ink' as a lyric from All the Rage 'don't try to touch my heart, it's darker than you think, and don't try to read my mind, it's full of disappearing ink', but 'unfaithful music' I had assumed was a metaphor for the fickleness of the music industry. However, its significance came to light when Elvis describes summoning a brass ensemble visiting the care home to perform 'Danny Boy' outside his dad's room (the song his dad had sung at Elvis's third wedding seven years earlier, stealing the show) only to have to ask them to stop when it proved intolerable to him. 'Perhaps there was no magic in this unfaithful music after all'. Perhaps.

Yet he persisted in playing music in his dad's room, believing intuitively that this would be preferable to silence. When I read his account of his leaving his dad's room one night while Fred Astaire's 'The Way You Look tonight' was playing softly in the background, turning to see his dad looking up and singing:

Oh but you're lovely

With your smile so warm

And your cheeks so soft

There is nothing for me but to love you.....

... before his voice trailed off, I thought my heart might break, as the curious pattern of water stains on pages 540 and 541 now attest. I actually thought that I might have to stop reading at that point, but there, just over the page, was my reward – my chink of light.

“As he slipped in and out of sleep over the next few days I tried to think of things we’d done together that might give him joy in a moment of recollection. I soon realised that I had exhausted our shared experiences very quickly. What lay between us was not measured in time”.

Ah, so there it is! I think maybe Julian Hughes had the answer all along – there is one human experience that does not require temporal awareness or ordering to acquire meaning – the spontaneous experience of authentic human love. And so it seems love has the first and final word in this reflection. What power.

I am not entirely sure what this all means yet, but I do know it is significant.

Back to good old Ricoeur – let’s see what he has to say about the limits of temporality and selfhood.

[This ‘limit’ didn’t make it into the body of the thesis, but became Appendix XVI]

The Long Road to Recognition – Getting to Grips with Ricoeur



Chrissie: Possible Plotline

NOTE TO SELF: It's about the Story Vs Applying Categories

There is an awful lot of stuff that relates to gender and gendered assumptions - appearance still important to her and her domestic and social caring roles, but in some ways, there is less female subordination – e.g. I am struck, based on the pressures that I experience, that there is 'no concept of 'in-laws'. **Overarching:** all about giving – but without sense of sacrifice or burden. Interplay between possibility and necessity. Relational agency – challenges individualistic assumptions – **'Corporeal Generosity'**. *Don't want to overplay the class and gender card – it's more complex than that! Narrative Inquiry – is about presenting storied lives in storied ways, not as exemplars of social structures and formal categories.*

Neighbours – One Possible Thread

Jessie and Elsie could have moved to the pensioners' houses in the past, but decided to stay together – Chrissie is literally sandwiched between them. She has become friends with them over many years.

Jessie does not install a stair lift because she does not like the idea and doesn't want to send out a message of being disabled to the world at large – (break-ins are common place). She falls down the stairs, does not regain enough mobility to return home (within current care at home provisions in Scotland) and moves into a care home.

Elsie is saddened by this. Elsie has a son who dutifully attends to her functional needs but, unlike Chrissie, she does not have a daughter to pick up on other more emotional and aesthetic needs. Elsie's son would not think to take her to visit Jessie and Elsie would never ask. [Gendered assumption here - but maybe also distancing?]

Chrissie values her relationship with Elsie. Elsie has provided a shoulder to Chrissie through some sad times in the past. Chrissie is responding to Elsie's sadness (the is result of something unplanned / unforeseen) with extra treats and she plans to take her to see Jessie on her birthday – giving Elsie something to look forward to – and also Chrissie: [Enacted togetherness - occupational possibility]. But again, Chrissie entertains the possibility that Elsie might move on too.

Family and Extended Family – Another Thread

Chrissie will need to soon stop driving and will be more restricted in her movements. (Helen is now 'having to' learn to drive, but is not finding it easy and Chrissie will be reliant on her). Craig may visit less. Chrissie can foresee this. Although Helen has moved in with her, Helen is working at present and has other commitments as a mother and grandmother.

Connection with above: Chrissie's daily visits to Elsie (an established routine) are taking on extra significance. Chrissie doesn't want Elsie to move on – as she may become more dependent on her

A Sub-Plot? Talking more to me about her deceased son, Kevin, including revealing that one grand-daughter is jealous of Craig, feels perhaps that he is a substitute for Kevin; that she's trying to replace him. [Life Review]

I am struck by the busyness of her life – talks to me when we find a rare oasis of calm — maybe the importance of having some time for quiet contemplation? Or purposefully evading this?

Has busyness been a buffer? She thinks about him Kevin daily... but wouldn't wish him back to life.

Holidays – spending time together now as a family while able to do it [sons' and daughter's circumstances lend themselves to this – all divorced] – sense of making amends for leaving her family when they were kids – but no opportunity to make amends with Kevin?

That's what families do' – occupational necessities – leading to occupational possibilities

Helen's moving in is as much about giving Natalie a place to live with the new baby as it is about Chrissie needing someone there for her – son next door, Helen out all day

Family members and others also make demands on Chrissie's time: **occupational necessities**

Trips to shops, bingo, swimming etc. enable me to see 'routines' and also 'functional coordination of problematic situations' in different settings. However, gain deepest insight into Chrissie's life (and how busy it is) as a result of being there at times when she had to change plans / was tied to the house in order to fulfil certain occupational necessities – for family members –

The 'busyness' of her days captured through the image of the opening and closing patio doors – or the constant ringing of the mobile phone. *It's like Piccadilly Circus – but that's the way we are and that's the way she likes it.*

- Pick up great-grandchildren from school at short notice and take them places
- Son has the car today because his is off the road ~ constraint
- Babysitting – including looking after the new baby (great grandchild)
- Overseeing the selling of the pram (Craig's mum) – 'I'll come round'
- Taking in Stanley because grand-daughter couldn't look after him properly and Chrissie was worried she might sell him to dog fighters (paying for his operation to have teeth removed)
- Managing the handover of the Yorkshire terrier puppies
- Giving daughter a lift to work 'they use you as a taxi service'
- Making arrangements to let a homeless friend stay in the house while on holiday
- Looking after Helen's pal's son with learning difficulties while they went to Cyprus
- Going to care for old boyfriend at the end of his life
- Helping daughter with cleaning jobs – ironing etc.
- Putting old wardrobes up on e-bay – and the need to be there for the handover

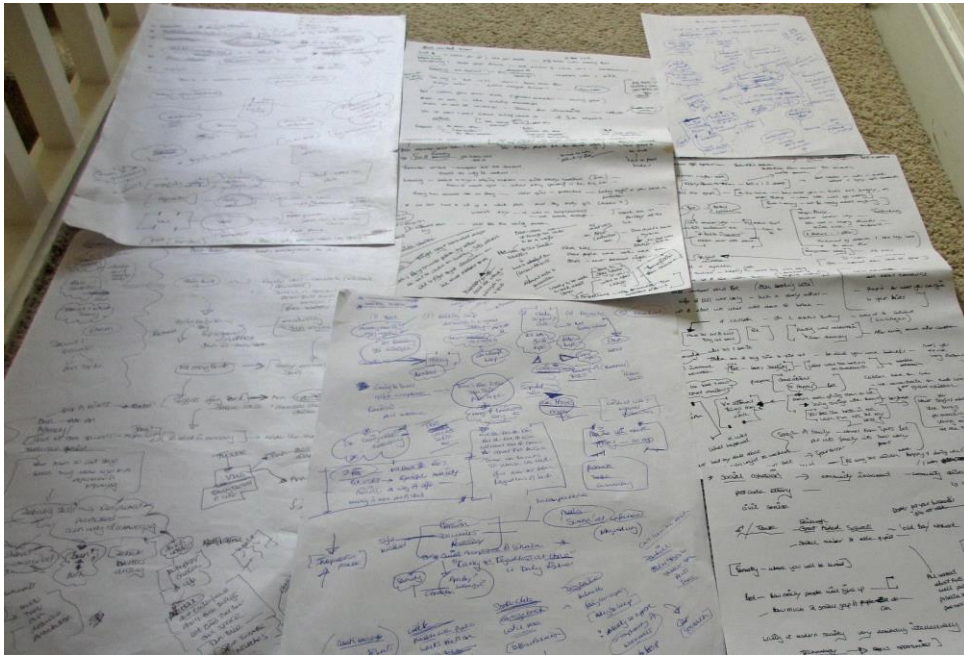
Chrissie reveals she has never really liked the place where she lives – she moved simply to be beside family. Daughter behind her – son next door. [Necessary?]

Contradictions: competing storylines re 'wanting to turn back the clock' to an idyllic moment in time – had to leave and 'you can't turn back the clock'.

Tommy – Initial Mapping with Post-Its

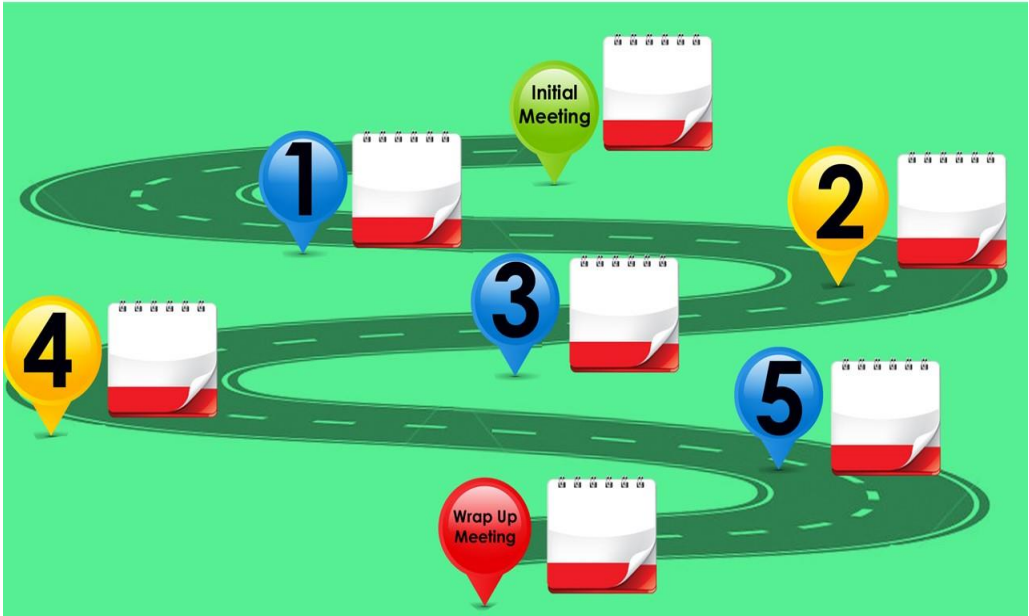


“Walkways? It’s taking over the house!”



Appendix XV: Visual Visit Record

Research Participation Record: [NAME]



Appendix XVI: Ricoeur on Temporality and Selfhood

Kitwood's (1990; 1997) work has been critiqued on philosophical accounts. In particular, Davies (2004) suggests that the philosophical starting point for discussions about the self should address the fundamental question of ontology, rather than the relations between subject and object world that fall more conventionally within the epistemological realm. He draws upon Heidegger's phenomenological perspective on *Being-in-Time* to challenge Kitwood's views that those without memories are merely disabled. Davis contends that losing memories is not anything that can be so simply palliated and trying to preserve personhood-without-memory, or rather, persons-without-awareness of their *Being* is more than a point of academic curiosity.

In *Oneself as Another*, Ricoeur (1992) considers what ontology of the self is in view. It is as if he anticipates the line of argument put forward by Davies. Ricoeur stresses that there are different levels of self-understanding. He rejects the direct route to self-understanding through introspection, favouring the long route through the Other.

For Ricoeur, attestation is the assurance by credence and trust of existing in the mode of selfhood acting and suffering. One of four primordial acceptations of being is acting. Self and Being-in-the-world are basic correlates – a ground at once (being and action) as both actuality and potentiality. He refers to Spinoza's notion of 'conatus', such that each thing in so far as it is in itself endeavours to persist in its own Being – to exist.

He develops his argument to state that self-consciousness is not the starting point as Descartes would have it. Rather, first is the passivity of the body or the flesh, second the otherness in relation to inter-subjectivity and then third the mostly deeply hidden, that of the self to itself – conscience. When considering the need to address deeply concealed forms of suffering including the incapacity to tell a story (p320) and other forms that go far beyond mishaps that can always be made meaningful through the strategy of emplotment, he attends to the lived body. The body denotes resistance that gives way to effort – the relational structure is wholly contained here as effort and resistance form an indivisible unity. The body receives the indelible significance of being my body- highlighting the experience of the active body illustrated by the dancer submissive to music alone, capricious humours – impressions of content or discontent and the resistance of external things. It is through active touch that things attest to their

existence as indubitably as our own. Existing is resisting – it is the same sense that gives the greatest certainty of our existence – one's body is revealed as the mediator between the intimacy of the self and the externality of the world.

His second point of reference is Husserl's ontology of the flesh and the body – inter-subjectively found in nature. He contends that Heidegger's 'Being-in-time' did not allow an ontology of the flesh to unfold. It is necessary to make the flesh part of the world if it is to appear as a body among bodies – the otherness of others, other than me, has to be interconnected not only with the otherness of the flesh. Ricoeur argues that it is because Husserl thought of 'the other than me' only as another me, and never the self of another that he has no answer to the question: *how am I to understand that my flesh is also a body?* Ricoeur suggests that Heidegger placed too much emphasis on fear and *Being-towards-death* rather than existence itself and his concern with the phenomenology of spatiality does not receive the attention it deserves. The unfolding of the problematic of temporality prevented this '*as though temporality were the exclusive theme of a mediation on authentic existence and the authentic features of spatiality were finally to be derived from those of temporality*'. He continues that Heidegger substituted the transcendental of the act for that of substance. Instead, the entire forefront of the ontology of selfhood must move in accordance with the three dimensions of otherness. (p328-329)

